

**Uncertainty, Family Responsibility, and
Supportive Nursing Care of Chronic
Heart Failure Patients and Their Families**

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DECLARATION

**I declare that the following thesis has been composed
by myself, and that the work is my own.**

Ellen Elizabeth Rukholm

DEDICATED TO

Toivo,
Kaylene,
Matti,
Jakob,
and Gavin

IN MEMORY OF

My Mom and Dad

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Many people helped to make this thesis possible. I would like to thank all those family members, colleagues, friends, and mentors for their support throughout this academic endeavour. However, the most important people to thank are the patients, families, and nurses who are the heart of this thesis.

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ABSTRACT

Despite the positive effects of recent advances in pharmaceutical therapy on the length and quality of life of chronic heart failure patients, the prognosis is poor with death usually occurring within five years of diagnosis. Shortened lengths of hospital stay can place much of the weight, of caring for the chronically ill person on the family.

Understanding the nature of the supportive nursing care needs of these patients and their families is critical to helping them live with this degenerative, life threatening chronic illness. As coordinators of patient care, nurses need this information to help in both the hospitalisation and post discharge rehabilitation phases of illness. Little research has been done concerning patients and their families in a chronic heart failure situation and the theoretical basis of much of the work done to date is limited because of the lack of a theoretical basis pertaining to the family.

The aim of this thesis was to explore patients', families', and nurses' perceptions of supportive nursing care provided by nurses to patients and their families during acute episodes of chronic heart failure and on a day to day basis at home. The research purpose was to gain knowledge that would advance understanding of supportive nursing care and contribute to a family derived theoretical basis for family nursing. Accordingly, a qualitative study of chronic heart failure patients, their families and nurses in acute and rehabilitative settings was undertaken using a grounded theory approach. Comparative analysis of the data led to the emergence of two major categories: uncertainty and family responsibility.

The properties, conditions, and consequences of uncertainty, family responsibility, and supportive nursing care are explicated in the development of a

theory of supportive nursing care for patients and their families. Uncertainty represents the context within which family responsibility and supportive nursing care are situated. Family responsibility for taking care of and protecting the patient emerged as a response to the uncertainty of a chronic life threatening illness under conditions of deteriorating health. Consequences of family responsibility involved major adjustments in living arrangements, relationships and activities of daily living that reflect the reciprocal relationship between the illness and the family and the family and the illness and demonstrate the utility of systems theory as a foundation for family nursing. Supportive nursing care for patients and their families evolved as an integration of physical, emotional and informational support to create a healing environment in which patients and their families feel comforted and reassured.

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CHAPTER 1

INTRODUCTION

Background

My interest in the needs of family members of hospitalised individuals began as a young teenager when my grandfather died. At the time children, even young adolescents, were not allowed to visit hospitalised members of the family. I vividly recall sitting in our family car on a hot summer day waiting for my parents to return from visiting my grandfather. Shortly thereafter, he died in the hospital of a stroke. My brothers, sisters, and I never saw him again. Our exclusion from his illness and hospitalisation triggered my later interest in cardiovascular illness, the family and nursing.

On completion of my nursing education, I practised as a paediatric nurse on a cardiovascular ward. As a young nurse I was fortunate to work in a paediatric hospital setting where visiting hours were open and family members were not only encouraged to visit but to participate directly in the care of their ill child. Including family in patient care became a normal part of my nursing practice. I left paediatric nursing and pursued studies in acute coronary and intensive care nursing of the adult in Australia and worked there for two years in a small intensive care unit. Although there were no formal nursing care plans, it was common practice to include family members in patient care. There was no formal policy or directive that stated families could visit at any time or be included in the care of their ill relative. However, neither were there any restrictions on family visiting—rather a relaxed, humanistic atmosphere prevailed that instinctively included family.

On my return to Canada, it quickly became apparent that the family had limited access to their ill relative in the intensive care areas of the hospital. Restrictive visiting policies were applied in the belief that the patient needed to be in a restful environment that minimized stress. Indeed, across North America most hospitals had policies that limited visiting in intensive care units to family members for five minutes every hour. These restrictions were applied in the belief that they were helpful to the patient. However, at a time when the patient was critically ill and with possible death imminent, limiting family visiting seemed senseless to me. My personal clinical experience in Australia suggested that both visiting and the inclusion of family in care could be quite beneficial to the patient and family. Some of the nurses I worked with in Canada were uncomfortable with a restrictive family visiting policy and were concerned about how to care for the family in life threatening, chronic illness situations.

While still working in the Coronary Care Unit (CCU), I began baccalaureate studies in nursing and in the final year of my program, I carried out a research project. The project that I undertook was a very unsophisticated, beginning effort at examining the relationship between the family, patient anxiety, and patient knowledge of illness in an acute cardiac illness situation. This early research activity laid the foundation for my master's thesis that again focused on patients and their families. My study examined the chest pain reporting behaviour of cardiac patients and their spouses using a symbolic interaction role theory framework (Rukholm, 1988; Rukholm & Bailey, 1989). I believed that families had an important role to play in the management and care of cardiac patients and was frustrated by what I felt was their exclusion. The needs of families and how patients and families managed care after being discharged from the hospital was an area that I also felt should be

examined. Post discharge management of care that included family seemed to occur by chance rather than by deliberate intervention.

Family Needs Research

On completion of my masters degree in nursing my interest in family research continued. I was fortunate to collaborate with two colleagues, one of whom had conducted a study of family needs of ICU patients in a French Canadian Quebec population. Together we developed a similar project in Sudbury, a predominantly English speaking community that has a minority French speaking population. The family needs study that was conducted in Sudbury replicated the Quebec research team's work with some minor modifications. Additional information about worries (pain, level of consciousness, tubes, etc.) was added because the literature and clinical experience suggested these were areas of concern for relatives. As well, the Sudbury study was bilingual whereas the Quebec study was carried out entirely in French.

After receiving a research grant we began the process of hospital ethics approval, data collection, and analysis. As primary recipient of the grant, I conducted the majority of the hospital interviews and carried out the data analysis. All family members were interviewed but only in the acute care setting and only as individuals. There was no attempt to capture family group responses. The quantitative nature of the data collection instrument, the Critical Care Family Needs Inventory, precluded the collection of data about patient, family, and nurse perceptions of the illness situation or about the nursing care provided. Our work produced a research report and several articles that identified the needs of family members. However, it did not include nurse and patient views nor did it explore the

meaning of supportive nursing care from the perspective of each of these players, in the illness situation.

Family nursing research in acute illness situations has focused heavily on replicating variations of the Molter (1979) Critical Care Family Needs Inventory (CCFNI) with different patient populations (Rukholm, Bailey, & Coutu-Wakulczyk, 1991; Rukholm, Bailey, Coutu-Wakulczyk, & Bailey, 1991; Rukholm, Bailey, & Coutu-Wakulczyk, 1992). As well, family needs research has compared nurses' perceptions with family members' perceptions (Norris & Grove, 1986; Lynn-McHale & Bellinger, 1988; Forrester, Murphy, Price & Monaghan, 1990; Silva, 1987) and validated instruments to measure family needs (Leske, 1988; Cipriano, 1987; Chartier, Coutu-Wakulczyk, Rukholm, & Bailey, 1991). Three grounded theory studies (Artinian, 1989; Cozac, 1988; McRae & Chapman, 1991) were found that explored the experiences of family members of coronary artery bypass surgical (CABG) patients.

Chronic Heart Failure

Although Chronic heart failure patients and their families are a growing population they have received limited attention and are often excluded from cardiac rehabilitation or palliative care services. Cardiovascular disease is the major cause of death and disability in Canada today accounting for 39% of all deaths annually (Heart and Stroke Foundation of Canada, 1993). As well, there is a high prevalence of congestive heart failure. Some researchers indicate that 50% of those diagnosed with heart failure die within the first year of diagnosis (Luchi, 1989) while others (Jackson, 1991) suggest that 50% die within five years and only 10% survive to 10 years.

Chronic heart failure is typified by medical crises, symptom control (dyspnea, fatigue, cardiac pain etc), complex treatment regimens, role changes, social isolation, and financial concerns (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Wiener, 1984). Chronic cardiac illness can be classified as "relapsing" or "episodic" (Rolland, 1987) in that episodes of acute, potentially life threatening failure accompanied by severe symptomatic distress can occur at any time and require emergency treatment and hospitalisation (Jackson, 1991; Luchi, 1989).

Chronic illness has major implications for the ill person and his/her family. "Most care for illness is delivered not in biomedical institutions or by professional practitioners but by the family and this family sector of care is where illness exacerbation is first identified and coped with" (Kleinman, 1988, p.179). Frequently, a family member is the major caregiver and the family unit must deal with potentially fatal health crises. They must also help manage the medical regimen and the social and emotional consequences of chronic illness on a day to day basis (Kleinman, 1992). Isolation from social contacts outside the family may occur because of characteristics of the illness and treatment regimen such as fatigue, activity restrictions, and medications such as diuretics. Hence, social relationships may be altered considerably. Jackson (1991) indicated that retirement is desirable for individuals with chronic congestive heart failure. However, inability to return to work may result in partial or total loss of income so that the financial resources of the family may be affected. Finances may be a problem because multiple medications are often extremely costly and not covered by health care plans. Gilliss, Highley, Roberts, & Martinson (1989) stated that the family has a "powerful influence on individual compliance with treatment and related clinical status"(p.6).

Dealing with the episodic nature of chronic cardiac illness with life threatening acute episodes may be difficult for family members because of the frequency of shifts from crisis to non-crisis and concern about when the next episode might happen. This ambiguity may lead to a number of different behaviours on the part of family members such as excessive vigilance, over-protectiveness, or withdrawal (Speedling, 1982; Rolland, 1987). The ultimate outcome of chronic cardiovascular illness for the family includes the ill person's eventual death and the loss of relationships.

In times of economic constraints, shortened lengths of hospital stay, and reduction in nursing staff, understanding how health care professionals can effectively support families in the management of chronic illness is paramount. In addition, the prevention of avoidable re-hospitalization for their chronically ill family member is critical. Shortened lengths of hospital care place much of the weight of caring for the chronically ill on the family (Gilliss, et al., 1989; Thorne, 1988). As nurses view their role as including support for the family in chronic illness situations, then exploration of the family unit experience is appropriate. Including family in patient care helps the family unit to cope with the experience (Gilliss, 1984; Dracup, Meleis, Baker, & Edlefsen, 1984). In order to make effective use of the limited amount of time available for interaction with families, nurses need to know more about families' perceptions concerning the support/help they want from health care professionals. As coordinators of patient care, nurses need this information to make key interventions in the hospitalisation phase as well as in the post discharge rehabilitation phase.

Thesis Structure

In Chapter 2, I introduce a review of the literature relevant to chronic illness frameworks, the characteristics of chronic congestive heart failure and the previous research that has been done in the area of family needs research. The most widely used approach to the measurement of family needs has been the Critical Care Family Needs Inventory. Support is a category within the Critical Care Family Needs Inventory, however, support lacked a theoretical definition. The CCFNI was derived from interviews with nurses. Neither patients nor family members were consulted to formulate the CCFNI. In addition, little work has been done with the growing congestive heart failure population and no research has been done with families as a group with this patient population. The discussion pertaining to chronic illness demonstrates that the Strauss, et al. (1984) chronic illness framework provides a way of examining the nature of chronic illnesses.

Chapter 3 describes the qualitative paradigm in general and then focuses on a description of and justification for the method used in this study. The method used is a modified ethnographic approach for data collection combined with a comparative analysis approach from grounded theory for data analysis. The chapter also elaborates on issues concerning the evaluation of the quality of qualitative research relevant to my study. Chapter 4 outlines the study setting, participants, and data collection process. In addition, the chapter discusses the analytic framework developed and used for data analysis.

Chapters 5, 6, 7, and 8 present the analysis of the study data. Specifically, Chapter 5 delineates family profiles. Chapter 6 provides an analysis of the major category of uncertainty as experienced by patients and their families at various points in time in the illness trajectory. Chapter 7 delves into family responsibility, a

concept that arose from the data concerning the adjustments or changes made by family members in response to their overwhelming sense of responsibility to take care of and protect the patient. Chapter 8 integrates and analyses patient, family, and nurse accounts of supportive nursing care in ICU, on the floor, and in the cardiac rehabilitation programme.

Chapter 9 presents discussion concerning family nursing theory and then elaborates the new knowledge gained on uncertainty, family responsibility, and supportive nursing care. In addition, Chapter 9 considers issues that arose during the study in relation to the development of family nursing theory and draws conclusions about supportive nursing care and family nursing grounded in the patient, family, and nurse interview data. Finally, Chapter 9 closes with implications of this work for family nursing theory, practice, and future research.

CHAPTER 2

LITERATURE REVIEW

The literature review centers around key concepts relevant to the study including chronic illness, the family, family needs, and supportive care. Initially chronic illness is discussed in general terms and then linked to the particular illness, chronic heart failure.

The causes, pathology, symptoms, and treatment of chronic heart failure are outlined to provide insight into the devastating effects of this illness on individuals and their families. Definitions and discussion of the various approaches to studying the family in a chronic illness situation are explored. Uncertainties about defining the family as context for the ill patient, the family as a unit of interacting members, and the family as a system interacting with other systems are discussed as they pertain to the current study. Little research has been carried out on individuals with chronic cardiac illness or their families. Hence the family needs research in the acute care area is reviewed and the contribution of that research to the development of this study is made. Pertinent elements include a critique of the assessment of family needs, the lack of a family derived theoretical basis for the instrument used to measure family needs, and the congruence between family and nurse assessments of the importance of family needs. Family needs are linked with the idea of supportive care. Supportive care provided either by the family or the nurse has been studied minimally in the chronically ill cardiovascular patient population.

The literature review was initiated with a CD-ROM medline search of literature published from 1988 to February 1998. Key words used in the literature search were family, chronic cardiac illness, congestive heart failure, family needs and support. As well, some studies came from literature searches done for previous work (Rukholm, Bailey, Coutu-Wakulczyk, & Bailey, 1991) while others were discovered serendipitously. For example, a study of cardiomyopathy patients and their spouses (Bohachick & Anton, 1990) was not identified in the medline search but happened to be in the same issue as another article that did arise from the medline search.

Related Cardiac Family Research Studies

Family focused cardiac research that has been done includes family visiting in intensive care (Stillwell, 1984), the impact of family on adherence to treatment regimens (Miller, et al., 1982), and the impact of family on chest pain reporting behaviour of hospitalised cardiac patients (Rukholm, 1988). As well, there is a substantive amount of work in the psychology and socio-medical literature that has dealt with spousal influence on symptom reporting and help-seeking behaviour of myocardial infarction patients. In addition, a number of studies have been carried out over the last twenty years that have looked at both myocardial infarction patients' and their spouses' psychosocial responses to the acute myocardial infarction event in-hospital as well as post hospital discharge in the rehabilitation phase (Rankin, 1992; Skelton & Dominian, 1973; Mayou, Foster & Williams, 1978). Hence most of the research done has been carried out in either acute care or rehabilitation settings with myocardial infarction or coronary artery bypass graft patients and their families (Dracup, Meleis, Baker, & Edlefsen, 1984). Very little research has been done with chronically ill cardiac patients and their families which was the focus of my research.

Chronic Illness

Chronic illness is increasingly a major concern for nurses and other health care professionals. The first part of this century was dominated by acute infectious diseases as the leading causes of morbidity and mortality. The advent of antibiotics combined with public health measures have virtually eliminated acute infections as a major cause of illness and death in the western world. In the latter half of this century chronic disabling illnesses such as cardiovascular disease have become the leading causes of sickness and death.

There is wide variation in the nature of chronic illnesses as evidenced by an early definition put forth in 1956 by the American Commission on Chronic Illness (Mayo, 1956, p.9):

All impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible, pathological alteration, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation, or care.

The above definition is helpful because it acknowledges the long-term and rehabilitation aspects of chronic illness. Limitations of the definition include the heavy emphasis placed on the medical aspects of a chronic illness, failure to account for a downward progression of chronic illness that culminates in the person's death and lack of recognition of family involvement in the care of the sick person.

Another definition, put forth by Lubkin (1990) is useful because it incorporates the notions of supportive care and self-care. "Chronic illness is the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function,

and prevention of further disability" p.6. Again however, the downward trajectory and eventual terminal nature of chronic heart failure are not evident in this definition nor is the role of family explicit.

On the other hand, the definition provided by Thomas (1984) incorporates both elements that are missing from the two previous definitions and was therefore used in my study. Thomas (1984) provided a broader view of chronic illness trajectory that includes a downward, episodic and potentially fatal path. Furthermore, Thomas incorporated the idea of individual and family management of chronic illness:

any impairment interfering with individual ability to function fully in the environment. In this sense, chronic illnesses are generally characterized by relatively stable periods, often interrupted by acute episodes requiring medical attention or hospitalization. Prognosis varies from normal life to unpredictable, early death. Chronic conditions are rarely cured, but are managed through individual and family effort (as cited in Hanson, 1987, p.12).

For a long time chronic disabling illness has been viewed in relation to survival and treatment response (Padilla, et al., 1983; Ware, 1984). However, it has become increasingly evident that for individuals experiencing irreversible and incurable illnesses, care needs to include and focus on aspects other than the disease process alone. Socio-cultural and behavioral factors have considerable effect on the expression of illness and the ill person and the family's response to it (Feldman, 1974; Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Wiener, 1984).

Chronic illness may be viewed as a major life crisis that results in many biological, psychological and sociological losses (Rolland, 1988). There are no pat answers or clear cut expectations of how those affected adapt (Craig & Edwards, 1983). Feldman (1974) suggested that in chronic illness the crisis is ongoing with

little or no hope of return to the pre-sickness state. He further suggested that the chronically ill person is faced with learning to accept self as different and that the major role of the health care worker is to facilitate adaptation to differences in all spheres.

It becomes apparent that long term illness should be considered from more than just a medical perspective. Rolland (1988) described a complex bio-psychosocial typology for chronic illness that includes onset, course, outcome, and degree of incapacitation of illness. This author depicted chronic illness as having three stages—crisis, chronic, and terminal. Furthermore, Rolland (1988) suggested that chronically ill individuals and their families are confronted by particular tasks at each stage. In Rolland's typology the interface between family and chronic illness is influenced by family illness beliefs, family transgenerational history of coping with illness, loss, and crisis and the interface of the illness with the individual and family developmental stage.

Rolland's depiction of chronic illness as being comprised of stages suggests a linear progression from crisis to chronic to terminal stage. This typology of stages may not be useful for chronic illnesses such as chronic heart failure where crises are recurring, unpredictable and are a crucial part of, rather than separate from Rolland's chronic stage. Hence, although Rolland's idea of episodic crises is relevant to my study, his idea of three stages may or may not be particularly helpful. On the other hand, while Strauss, et al. (1984) also take a task approach to the individual and family management of chronic illness, these authors do not specify particular stages or phases of illness. Strauss, et al. (1984) have proposed the following framework for viewing the work of ill individuals and their families in managing chronic illness:

1. The prevention of medical crises and their management once they occur
2. The control of symptoms
3. The carrying out of prescribed regimens and the management of problems attendant on carrying out the regimens
4. The prevention of, or living with, social isolation caused by lessened contact with others
5. The adjustment to changes in the course of the disease, whether it moves downward or has remissions
6. The attempts at normalizing both interaction with others and style of life
7. Funding--finding the necessary money--to pay for treatments or to survive despite partial or complete loss of employment
8. Confronting attendant psychological, marital, and familial problems (p.16).

The Strauss, et al. (1984) framework takes into account the long-term nature, the prognosis, the particular course (episodic, progressive, fatal), the disruption of individual and family members' psychological and social lives, the financial cost incurred and the often palliative nature of chronic illness. The framework is particularly useful because the categories focus on the work of patients and their families whereas other frameworks such as that of Rolland (1988) provide a very complex typology of chronic illness that lacks the specific individual and family task orientation provided by Strauss, et al. (1984). The framework goes beyond the medical implications of managing chronic illness by also considering day to day psychosocial implications. Hence, Strauss's framework was used to theoretically inform the structure of the interview process.

Chronic Cardiovascular Illness: Chronic Heart Failure

Cardiovascular disease is the leading cause of morbidity in the western world including Canada. "Each year in Canada, 40,000 people are diagnosed for the first time as suffering from congestive heart failure" (Heart and Stroke Foundation of

Canada, 1993). Chronic heart failure is increasingly a sequel of ischemic and other heart diseases. Currently heart failure is the leading cardiovascular diagnosis for hospitalisation and readmission (Krumholz, et al., 1997). Not only has the incidence of heart failure been steadily rising around the world over the past 18 years (McMurray, McDonaugh, Morrison, et. al., 1993; Heart and Stroke Foundation of Ontario, 1997), but it has also been predicted to continue climbing in the future. The increased survival of heart disease patients combined with aging of the “baby boomers” is expected to result in ongoing acceleration in the incidence of this condition. Bonneux, et. al., (1994) have predicted that the number of people diagnosed with congestive heart failure will continue to increase over the 1985-2010 time period. The majority of heart failure patients are on a downward chronic illness trajectory with as many as 50% dying within the first year of diagnosis (Hawthorne & Hixon, 1994; Luchi, 1989). Since half of the people suffering from heart failure do not live past five years from the time of being diagnosed, living with heart failure is more than a question of survival. Living with heart failure has physical, psychological and social implications for individuals and their families that have received minimal attention in the research literature.

One of the problems with chronic heart failure (CHF) is the frequent and often unpredictable occurrence of potentially life threatening episodes of acute illness that require hospitalisation. These individuals have the highest readmission rates for all patient groups (Hawthorne & Hixon, 1994; Krumholz, et al., 1997). In fact readmissions often occur only weeks after hospital discharge.

Vinson and colleagues (1990) noted that 38% of hospital readmissions of heart failure patients were considered to be 'possibly preventable' while 15% were

considered to be 'probably preventable'. It is unclear whether or not these readmissions are truly preventable since the criteria used for preventing readmission were entirely subjective. Indeed it is also questionable whether or not preventing readmission should be a goal. Readmissions may offer respite for families and give the ill individual the opportunity to be reassessed and if necessary to have treatment adjusted. Furthermore, Tierney & Worth (1995) suggested that readmission has been defined in a variety of ways. These authors recommended a clear definition that discriminates planned from unplanned readmissions, that separates data on single and multiple readmissions, and that separates readmissions from new admissions. Tierney and Worth (1995) also emphasised the need to study the consequences of readmission as opposed to the event itself. Even though Vinson, et al. (1990) suggested that as many as one third of rehospitalisations might be prevented, very little is known about how individuals with CHF and their families deal with their illness either in crisis situations or on a day to day basis.

The words of Strauss, et. al. (1984) reiterated the need for understanding how the chronically ill manage both inside as well as outside the hospital.

Without understanding a great deal about how the chronically ill get through their days outside of health facilities (and inside them too), health personnel will never understand what they really need to know to give effective care at the facilities--and to ensure that the patients will not return more quickly than they should (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek & Wiener, 1984).

What happens when heart failure develops? In simple terms the heart is unable to efficiently pump enough blood to satisfy body requirements for oxygen. The amount of blood expelled with each contraction of the heart is reduced. This usually

happens during times of emotional or physical stress, however, it can also happen at rest.

Causes. Heart failure usually occurs because of other problems, the most common being myocardial infarction, chronic high blood pressure, valvular heart disease or a congenital heart defect. It can also be the result of viral disease or alcoholism that has caused damage to the muscle of the heart resulting in cardiomyopathy (Braunwald, 1991; 1994). Heart failure can result from systolic or diastolic dysfunction. Systolic dysfunction generally occurs because the heart's ability to contract diminishes, usually following a myocardial infarction. The pumping action of the heart muscle is not able to generate the strength needed to propel enough blood out of the heart and into the circulatory system. The ejection fraction—the amount of blood propelled forward into the circulation during systole compared to the amount of blood left in the heart at the end of diastole—drops below 40%. A decreasing ejection fraction leads to increased pressure in the pulmonary venous system resulting in pulmonary congestion and shortness of breath. The reduced cardiac output means that peripheral muscles do not receive adequate oxygen and the patient feels weak and fatigued. In diastolic heart failure the heart's capability to relax is reduced because of left ventricular hypertrophy, or hypertension or other conditions that cause the heart muscle to lose the ability to relax. In this type of failure, a higher quantity of blood is needed in the ventricles to preserve cardiac output. Pulmonary congestion and peripheral edema ensue. Systolic failure is more common than diastolic failure.

Treatment. Few patients are eligible for heart transplantation and hence most are confronted with a chronic, incurable illness managed through symptom control. Care focuses on maximising function, reducing morbidity, and lengthening and

improving quality of life. Medical treatment goals include relief of symptoms of fatigue, breathlessness, and angina which are significantly disabling for the patient (Hawthorne & Hixon, 1994). Treatment is generally complex involving diet, multiple medications and activity limitations (Rideout, 1992).

Consequences. The impact of CHF can vary considerably but there is no doubt that in addition to physical consequences there are also psychological and social consequences. The illness is episodic so that the occurrence of illness events is variable. When the next crisis episode will occur is not predictable and could affect how the individual and family will handle crisis illness episodes. Another consequence of the illness is stress. There is the stress of living with and managing heart failure on a day to day basis and the stress of living with the knowledge that the eventual outcome of the illness is death. I was unable to find any research concerning whether or not eventual death is ever discussed with patients and their families as an outcome of this chronic illness. Nor have I discovered any research that addresses whether families and patients think about, or acknowledge this eventuality. Apart from the potential for death the illness also leads to functional losses and social isolation.

Physical impact. Changes in ventricular function, preload and afterload, lead to the common signs and symptoms of anorexia, edema, fatigue, shortness of breath and weight gain (Braunwald, 1991, 1994). Exacerbations of symptoms are partly the result of progression of the disease. However, acute episodes of failure may be precipitated by alterations in such modifiable lifestyle factors as activity, medication adherence, and diet as well as, medical factors such as anemia, arrhythmia, infection, pulmonary embolism and thyroid disease (Braunwald, 1991, 1994).

Hawthorne and Hixon (1994) conducted an interventional study of 29 chronic

heart failure patients enrolled in a rehabilitation programme. The control group received standard nursing care while the experimental group received standard care plus a special symptom management component. Subjects were mailed a questionnaire that measured mood, uncertainty, functional status, and quality of life on entry to the heart failure rehabilitation programme, and again when subjects had been in the programme for one month, three months, and 6 months. Although physical activity tolerance would logically seem to be related to the severity of illness, it is important to note that Hawthorne and Hixon (1994) found no relationship between reported exercise tolerance and ejection fraction. Ejection fraction is the percentage of total ventricular volume ejected during each contraction of the heart and is often used as a measure of ventricular function; normally it is greater than 55% and usually it is approximately 65% (Underhill, Woods, Froelicher, & Halpenny, 1989). As the ejection fraction diminishes, pressure builds in the pulmonary venous system, causing pulmonary congestion and shortness of breath.

In the same study (Hawthorne & Hixon, 1994), found that mood disturbance was related to activity levels. That is, the lower the activity level the greater the mood disturbance but activity levels were not related to a measure of the pathology of failure (the ejection fraction). The impact of the physical consequences of heart failure on mood in this small sample supports the need to increase our understanding of the psychosocial implications of the management of heart failure (Hawthorne & Hixon, 1994). These researchers suggested that physical function and psychological impact of illness could not be separated in their sample.

Psychological impact. Much of the work to date concerning the psychological impact of cardiovascular illness has focused on myocardial infarction

patients and their spouses and has revealed that anxiety and depression are common in both spouses and ill family members. Mayou, Foster, and Williamson (1978) reported that the wives of myocardial infarction patients experienced emotional distress similar to their spouses. A more recent study by Bohachick and Anton (1990) examined the psychological distress of 90 chronically ill cardiomyopathy patients and their spouses. These researchers found that couples experienced considerable psychological distress with spouses reporting even more psychological distress than patients. Spouses reported more worry than patients (82% vs 56%), more anxiety (61% vs 40%), and more depression (39% vs 20%). Hence it can be seen that a chronic cardiovascular illness can have considerable psychological impact both on spouses and their ill partners. Although Bohachick and Anton (1990) provided worthwhile information concerning the psychological status of these chronically ill cardiac patients and their spouses, they did not consider the day to day management of the illness.

In the previously mentioned study by Hawthorne and Hixon (1994), heart failure patients reported significant mood disturbance that seemed to be even worse than that experienced by other kinds of cardiac patients. As well, heart failure patients were found to have higher uncertainty in illness scores than myocardial infarction patients or other kinds of patients reported in other studies. Findings also suggested that the more uncertain the course and treatment regimen the greater the mood disturbance. The authors also discovered that mood disturbance was inversely related to the subjects' perceptions of family quality of life. Hawthorne and Hixon (1994) felt this finding indicated that the quality of emotional support from family may have a significant impact upon a patient's emotional state. On the basis of this finding,

these researchers identified a need to study the impact of chronic cardiovascular illness on families.

Limitations of Hawthorne and Hixon's (1994) work revolve around the very small sample size and the use of instruments that excluded individuals of low literacy level. As well, although the authors suggested completion of these instruments took only 30 minutes, they are long, complex questionnaires which likely took much longer to answer. The authors themselves indicated that the length and complexity of the questionnaire likely led to incomplete data especially since this patient population is characterised by chronic fatigue. In particular data gathered from the Quality of Life Index-Cardiac III is questioned. However, despite these drawbacks this work does suggest the need to study chronically ill cardiovascular patients and their families.

Social impact. The social impact of chronic heart failure is far-reaching and carries many implications for patients and their families. The illness may result in loss of employment for the patient and sometimes for the spouse as well. Role changes in work and leisure may well ensue.

Bohachick and Anton (1990) in their study of the social adjustment of 90 patients and their spouses to severe cardiomyopathy found that 77% of patients reported that they were no longer able to work because of their illness and 12% of their spouses said that the patients' illness prevented the spouse from working. Although 71% of spouses reported negligible job problems, 41% said they had altered their career goals because of their partners' illness. Furthermore, family income was more affected as compared to myocardial infarction (MI) patients (Dhooper, 1983). Cardiomyopathy family members were more likely to have a slight or moderate drop in income (65%) as compared to MI family members (30%) and

severe hardship was also reported to be higher for cardiomyopathy family members (18% vs 7%). There is every reason to believe that financial concerns increase as the illness progresses. Indeed, the Heart and Stroke Foundation of Canada (1993) reported that "about 20% of disability pensions paid by the Canada Pension Plan in 1992 to individuals up to age 65 were for cardiovascular disease, second only to payment for musculoskeletal disability (34%)".

Not only were the work careers of these individuals and their spouses altered but Bohachick and Anton (1990) also found their social lives severely diminished. Patients reported a decrease in individual, family and leisure activities of 70%. Furthermore, their spouses reported an equal amount of diminished social and leisure time activities.

Chronic illness is increasingly becoming the dominant form of illness in western society. There is limited knowledge of the biopsychosocial implications of chronic cardiac illness for patients and their families. The interface between chronic illness and family must be addressed if the nurse is to function in a supportive role.

The Family

Family was viewed as more than context for the care of the chronically ill patient. It was recognised that not all patients have families or are cared for by families. However, for the purposes of my study, family was seen as central to patient care. The family is more than context for the ill patient, it is also a system comprised of individuals in interaction with each other and with the surrounding environment (Friedemann, 1989). In times of shifting beliefs and values about what constitutes family, it is evident that the traditional legal and/or biological definitions are no longer adequate. However, without legal and/or biological definitions it is difficult to

provide a definition of family that makes it more than simply a supportive group. Ultimately, it is the "persons within the family who mutually define themselves and each other as members of families" (Gilgun, et al., 1992, p. 23). A number of different definitions of the family have been described in the literature. Each of these definitions suggests that there is more to the definition of family than the traditional legal and biological factors. Gilgun, et al. (1992) defined families as:

- a) persons mutually define themselves and each other as members of families,
 - b) members make enduring commitments to each other, and
 - c) members have a shared personal history.
- (Gilgun, et al., 1992, p.23)

Stuart (1991) used the concept analysis method outlined by Walker and Avant (1988) to analyse the concept of family. This method of scrutinising a concept involves eight steps including: 1) selecting a concept; 2) determining the aim or purpose of the analysis; 3) identifying all uses of the concept that you can discover; 4) determining the defining attributes; 5) constructing a model case; 6) constructing borderline, related, contrary, invented, and illegitimate cases; 7) identifying antecedents and consequences; and 8) defining empirical referents (Walker and Avant, cited by Stuart, 1991, p. 31.) After her analysis of the concept of family, Stuart (1991) identified the following critical attributes:

- 1. The family is a system or unit.
- 2. Its members may or may not be related and may or may not live together.
- 3. The unit may or may not contain children.
- 4. There is commitment and attachment among unit members that includes future obligation.
- 5. The unit caregiving functions consist of protection, nourishment, and socialization of its members.

(Stuart, 1991, p.40)

The family may be viewed as context for the individual or it may be viewed as a "unit" or whole, an entity with personality, characteristics and function of its own that are more than the sum of the parts according to Frude (1990). Other authors offer a different way of defining "unit". Burgess (1926) defined the family as a unit of interacting personalities, while Turner (1970) defined family as a system of interlocking roles. These latter two definitions emphasise interaction between members of a group (Maurin, 1983) and as such, were particularly relevant to my study.

Family Models

In addition to definitions of family there are a number of models or frameworks that have been devised to conceptualise the family. Clearly there must be a fit between the definition of family and any family model that influences the conceptualisation of a study. Four models are frequently mentioned in the family literature including adaptation, developmental, and symbolic interaction models, as well as, general systems theory (Hanson, 1987). Each of these models is relevant to the study of families within the context of chronic illness. However, it is my belief that no one model can comprehensively address the myriad of concerns and issues confronting the family with a chronically ill member. Hence an eclectic approach that capitalises on the unique contributions of each is perhaps the most helpful for the purposes of my study.

Chronic illness can be viewed as a major stressor to which the family responds and adapts. Rolland (1988) defined family adaptation as "the ability of a family to transform its entire life structure to a prolonged transitional state" (p. 65). In terms of the developmental stage of the family, chronic illness may pose an added stressor for

families in transition (Rolland, 1988). Symbolic interaction looks at both the individual within the context of family as well as at interactions between members, while general systems theory looks at subunits within the family and also at the connection between the family as a unit and other larger systems outside the family.

Two of these models, symbolic interaction and general systems theory seemed particularly helpful. The contribution of each of these models to the development of my study follows.

Symbolic Interactionism

Symbolic interactionism is a term used to describe a particular way of studying groups of people. George Herbert Mead was a scientist and a philosopher who provided 'the ideational and conceptual structure' of a social philosophy that located human behaviour within social interaction (Mead, 1934, p. xi). Blumer (1969) credited Mead as having established 'the fundamental premises of the symbolic interactionist approach' (p. 78). Blumer advanced the philosophical work of George Herbert Mead by developing the methodological consequences of symbolic interactionism for the study of human group life (Blumer, 1969, p. 78).

Symbolic interactionism is based on three main assumptions. The first is that "human beings act toward things on the basis of the meanings that things have for them". The second is that "the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows". The third and last is that "these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters" (Blumer, 1969, p.2).

Symbolic interactionism views meaning as coming from the process of interaction between people (Blumer, 1969). Meanings are created through people as they interact. Hence to understand the meaning attributed to supportive nursing care in the proposed study, interactions between people must be explored.

Symbolic Interactionism and the Family

The following are basic assumptions of symbolic interactionism applied to the family (Gilliss, 1989) that help to explain why this particular approach is helpful in the study of chronic heart failure patients and their families. Symbols (objects) have shared meanings that are acquired through living in a symbolic environment. People see, assess, and attach meaning to symbols. Behaviour is influenced by the meaning attached to symbols. Changes in the evolving nature of self occur through a reflexive activity within a social experience. There is a 'me' and an 'I' within self. 'Me' represents learned patterns and behaviours while 'I' is unique and spontaneous. Learned patterns and behaviours predominantly are derived from the family. Interactionist theory provides the ability to examine the family as a small group. Self comes from interactions with others. Family is usually the social group within which the individual defines self. The attitudes and problems of family become a part of the self.

General Systems Theory

Von Bertalanffy (1968) formulated general systems theory which has been used in a variety of disciplines ranging from business studies, to sociology, engineering and nursing. The theory purports that a system is made up of a set of interacting parts. Furthermore, systems are distinct from the environment.

Major concepts of general systems theory include wholeness, boundaries, and hierarchies. Other key aspects are homeostasis, feedback, and energy. Wholeness refers to the notion that the whole is greater than the sum of its parts and that there is interaction amongst the parts. Boundaries are the borders around the system. Boundaries have varying degrees of permeability ranging from open to closed. Boundaries control the movement of matter, energy and information in and out of the system. Hierarchies convey the idea that systems have subsystems and belong to suprasystems: that is, a person is a subsystem of family and community is a suprasystem of family. Elements of control in general systems theory include: homeostasis, feedback, and energy. Homeostasis is a steady state within the system—a process that keeps the constant flow of matter, energy, and information that moves in and out of the system balanced. Information, matter, or energy flowing into the system is called input while that flowing out is called output. Throughput refers to the process that changes input into energy needed by the system. The combination of input, throughput, and output is called feedback. Input affects output and output adjusts input to promote growth and development of the system. Feedback can be negative or positive. Negative feedback allows the system to correct aberrations whereas positive feedback intensifies the original input creating more energy.

General Systems Theory and the Family

General systems theory as applied to family emphasises an interaction oriented approach. Family is viewed as being comprised of members and the interactional patterns between members becomes of central concern. As a system the family has a boundary that allows or blocks entry of elements from the environment. The

permeability of the boundary determines the ease or difficulty outsiders experience moving into the family. Family is a subsystem of community and a suprasystem of each of the family members. Members interact and strive for balance (homeostasis). When the family is viewed as a system, understanding of what family norms are, how effectively family members communicate, how family members interact, how decisions are made, and how the family deals with individual member needs and expectation is sought (Wright and Leahey, 1994). My study is primarily concerned with the latter three.

Levels of Approaching the Study of the Family

Friedemann (1989) suggested that there are at least three levels of approaching the study of the family in a chronic illness situation. One can study individuals within the family context, or the interactions between dyads, triads and larger groups, and/or the family as a unit or system.

To date, much of the work pertaining to families in cardiac illness situations has looked at the impact of illness on individual family members, usually the spouse. Some work has gone beyond to the interaction level (Gilliss, 1991), however no nursing studies were found that actually studied the family as a unit or system. This may well be due to logistical difficulties of studying the family as a unit or system comprised of subsystems interacting with other systems. Gilliss (1991) described her own work with cardiovascular patients and their families. Gilliss (1984) studied subjective stress in 71 post operative coronary artery bypass surgical patients and their spouses at two different points in time. These were three to eight days post surgery and six months post hospital discharge. She carried out two semi-structured

interviews as well as a survey that measured subjective stress (the Impact of Event Scale) and reported significantly higher levels of stress in spouses as compared to patients. Using a regression procedure she attributed the difference to role (patient or spouse). Gilliss (1991) cited a paper that she presented on measuring subjective stress in families using the Impact of Event Scale in 1981 at the Fourth Annual Robert Wood Johnson Nurse Faculty Fellowship Symposium in Nashville, Tennessee. In reference to this paper she indicated that when mean stress scores of individual family members were compared to a family unit score, which the group reported, no differences were found in subjective stress between the group score and individual scores. Furthermore, she reported that another researcher has replicated her work with similar results. Gilliss (1991) offered two alternate explanations of these findings. First, that indeed there is no difference between the sum of the parts (individual members) and the whole (family unit). Second, that the methodology used to measure individual and family stress simply failed to capture the difference.

This is not to suggest that studying the family as a unit should be abandoned but it does suggest that there are difficulties inherent in attempting to study the family as a unit. Gilliss (1991) believed that family process can be studied by data provided by an individual family member. Friedemann (1989) suggested that studying the family as a unit at the systems level involves both studying individual members as well as interactions between members. She contended that individual and interactional approaches combined with an original intent to act at the system level can yield information at the family system or unit level.

Frude (1990) stated the need for both types of family studies—those of ill individuals within the context of family as well as those of the family unit. In the

literature there is a "lack of consensus about what should be evaluated and how selected methods might access the data that make the family unit more than the sum of its parts" (Gilliss, 1991, p.198). The focus of supportive care in my study is the sick individual and the impact of managing that illness on the family. However, the logistics of studying the family unit in an acute hospitalisation phase is very difficult if not impossible. The acuity of the ill family member alone could ethically preclude any family unit interview in the hospital setting. However, it seemed that for the purposes of my study the patient and individual family members could be studied.

Frude (1990) purported that the family unit is more than the sum of its parts. Hence, he contended that the study of individual members is not the same as studying the family unit. Individual family members may be studied within the context of the family or the family may be studied as a unit. Just exactly how one studies the family as a unit is again not clearly articulated by Frude (1990). In order to study the unit or system one must examine interactions between family members as well as interactions between the family unit/system and other systems.

I believe this division between family as context for individuals and the family as a unit is an artificial division. It is my experience that in an illness situation often one family member assumes the role of the main caregiver and as such often serves as spokesperson for the family unit when interacting with other systems like the health care system. The views of that spokesperson may or may not be representative of the family unit.

Friedemann (1989) raised the problem of harmonising the concepts of family and family nursing in relation to Fawcett's (1984) nursing metaparadigm. The metaparadigm of nursing refers to the global concepts of person, environment, health,

and nursing described by Fawcett (1984) as the fundamental elements of the discipline of nursing. The question is, where do family and family nursing fit in the metaparadigm of nursing? If the concept person is viewed as plural, then the patient is not just the individual but also the family, or even the community. If family is conceived as being an aspect of the patient's environment that has an impact on the person's health, then family becomes context for patient care. On the other hand, family could be considered simultaneously as an aspect of the concept person and the concept environment. Friedemann contended that the family should be understood as part of both, or the nursing metaparadigm expanded to include two more concepts—family and family nursing.

There is consensus emerging from the family literature that there needs to be congruence between the philosophical or theoretical stance the researcher adopts, the definition of family, the questions asked, and the methodology and analysis used to answer the questions (Feetham, 1991, p.57). "Nursing research questions that address the family unit need to be conceptually, procedurally, and analytically appropriate" (Gilliss, 1991, p. 205).

Key notions concerning the definition of family extrapolated from the literature helpful to my study included consideration of: a) the family as a system, b) the commitment between members, c) the interaction between members, and d) the function of caregiving. The family is more than context for the ill patient, it is also a system comprised of individuals in interaction with each other and with the surrounding environment (Friedemann, 1989). In a chronic illness situation interaction with the environment involves interaction with the health care system and in my study, with nurses.

Family Needs and Supportive Care

First the literature pertaining to family needs will be reviewed and then supportive care will be examined and relevant studies reviewed.

Family Needs

Research on families and their requirements for supportive care in cardiac illness situations has focused heavily on acute cardiac illnesses such as myocardial infarction in both the hospital and rehabilitation phases of illness. The majority of the work done during the hospitalisation phase of illness has focused on assessing family needs using variations of Molter's (1979) Critical Care Family Needs Inventory (CCFNI) with different patient populations, instrument validation studies, and comparisons of the congruence between nurses' perceptions and family members' perceptions of family needs. Methodologically, the majority of studies have been quantitative using the CCFNI, however, three grounded theory studies were found and these again explored the experiences of family members in acute cardiovascular illness situations.

The experience of patients and families living with chronic cardiovascular illness has received little attention. A limited amount of work has been done with patients experiencing chronic congestive heart failure, however, one study was found that examined spousal burden and strain in response to their mates' chronic congestive heart failure illness (Karmilovich, 1994). Much of the work dealing with support for families has emphasised the acute care illness situation and one family member. Hence, an overview of that work will be presented first.

Assessing family needs. Family needs have been assessed using the CCFNI which contains 50 statements pertaining to the concerns and requirements of family members of an acutely ill individual from the perspective of the health care professional. Family members have been asked to rate the importance of statements such as knowing about patient progress, prognosis, treatment, transfer plans, visiting arrangements, access to toilets, a telephone etc. Six concerns that have been consistently identified in a number of studies as most important to families include: to be assured that best care was given, to have questions answered honestly, to know specific facts about the patient's condition, to know how the patient was being treated, to be called at home about changes, and to know the prognosis (Hickey, 1985; Hickey & Lewandowski, 1988; Kleinpell, 1991; Simpson, 1989; Leske, 1991). Criticisms of the critical care family needs studies include the use of small convenience samples (Molter, 1979; Rodgers, 1983; Daley, 1984), limited reporting of psychometric properties (Molter, 1979; Bouman, 1984; Leske, 1988), failure to identify visiting practices and policies (Molter, 1979; Bouman, 1984; Daley, 1984), and the lack of a family-derived theoretical basis for the CCFNI. Using a theoretical framework to study family stress in an acute episode of chronic cardiac illness would assist with the organisation of the study and the interpretation of results (Simpson, 1989).

The needs identified in most of the previously mentioned family needs studies focused predominantly on the ill individual as opposed to personal needs of the family member. Similar to the findings of two earlier grounded theory studies (Artinian, 1989; Cozac, 1988), McRae and Chapman (1991) reported that families were not concerned with their own personal "needs" but rather with the care of their ill family

member. However, on reviewing the CCFNI these researchers did note congruence between their findings and some of the CCFNI statements. For example, accessing information and the family member's desire to help with patient care, were regarded by these researchers as similar.

Theoretical basis. The CCFNI has been criticised for lacking a family theoretical basis (Simpson, 1989). It is a limitation that the CCFNI was not developed by interviewing family members themselves but rather from a review of the literature and from interviewing 23 nurses doing graduate studies (Molter, 1979). Gilliss (1988) suggested that family members' perceptions about supportive care should be explored from the perspective of the family member. Although family members have rated the importance of these concerns in numerous studies, these needs did not originate from family members and the meaning family members attribute to them is unclear. Statements that refer to having questions answered honestly are ambiguous and could have various meanings for different families.

Several attempts have been made by researchers to provide a theoretical basis for the CCFNI. Silva (1987) tried to retrospectively fit Roy's nursing model with a Family Needs Inventory that had been adapted for use with family members of an abdominal surgical patient population. Through factor analysis Silva identified five dimensions of family needs. However, she found that the fit between Roy's dimensions and the dimensions determined by factor analysis of the Family Needs data base was incomplete. Furthermore, the use of factor analysis in Silva's study could be questioned on the basis of an insufficient sample size for this type of statistical analysis (factor analysis) since Silva's sample contained only 75 subjects. Usually a minimum of five subjects per item is considered acceptable (McDowell & Newell,

1987, p. 30). There were 45 items on the adapted Family Needs Inventory used by Silva. Hence, a sample size of 225 is the minimal requirement for factor analysis results to be considered rigorous. Consequently her work adds little to the theoretical basis of the assessment of family needs.

Chartier, Coutu-Wakulczyk, Rukholm, & Bailey (1991) also carried out factor analysis on Family Needs data gathered from relatives of an ICU patient population in two communities. Similar to Silva's work, five dimensions were identified and an attempt was made to explain these dimensions in relation to a "perception" model that looks at self-perception, the situation, and the human environment. However, the fit between these three dimensions and the five dimensions identified by factor analysis is unconvincing.

The difficulty with these theory building approaches of Silva (1987) and Chartier, et al. (1991) lies with retrospective attempts to force a fit between the dimensions identified by factor analysis with a theory when the original CCFNI questions were not based on either Roy's adaptation model or Chartier, et al.'s (1991) perception model. As previously mentioned Molter's (1979) original work in developing questions for the CCFNI was based on a review of the literature and input from 23 nurses pursuing graduate studies.

Family burden. As opposed to studying family needs Karmilovich (1994) examined family burden and stress associated with caring for individuals with heart failure. This descriptive survey of 11 male and 30 female spouses assumed that caring for an individual experiencing heart failure would result in burden and stress in the caregiver. No attempt was made to examine any counterbalancing satisfaction the caregiver might gain in such a situation. Spouses completed two valid and reliable

scales: the Caregiving Demands Scale and the Brief Symptom Inventory plus a demographic form. Findings indicated that spouses found the role of caregiver to be burdensome and stressful. The author recommends a qualitative examination of the experience of family caregivers of individuals who have heart failure. Generalisability of study findings is limited by the use of a small, convenience sample. Furthermore, the study fails to take into account that the experience of caregiving may not be burdensome but rather may lead to a greatly strengthened relationship between the caregiver and the patient. The dependence of the ill person on the caregiver may be balanced by the caregiver's satisfaction in being needed (Frude, 1990). The following quote affirms the shifts and changes that illness in one family member can precipitate in the family.

When constant care is necessary, structural changes to the family system are required and in particular one member of the family is likely to adopt the role of 'principal caregiver'. In some cases it will be obvious which person should take on such a role, but in other cases there may be difficult negotiations that are likely to be prolonged, intense, and intimate, and a nurse-patient sub-system is likely to have a forceful component of the adapted system. Frude (1990) p.80

Among the changes is the adoption of the role of caregiver by one family member which as previously noted in Karmilovich's study was found to be stressful and burdensome. As well, Frude (1990) envisioned a role for the nurse. In the role of providing supportive care, the nurse needs to be attuned to congruence between her own perceptions of supportive care and those of the patient and the main family caregiver. The work done to date has taken place predominantly in acute care settings and focused on family needs.

Congruence Between Nurses and Family Perceptions

Rolland (1988) suggested that it is critical to examine the congruence between health care professionals including nurses and the health care belief systems of family members. He placed heavy emphasis on the importance of understanding families' and health care professionals' own beliefs about the families' capability of controlling the course/outcome of the illness. As well, Rolland (1988) stressed the need to understand the fit between what health care professionals think the families' role is and what the family perceives its role to be in terms of treatment and control of the illness.

A few studies have compared nurses' perceptions with family members' perceptions of family requirements for supportive care in acute care settings (Norris & Grove, 1986; Lynn-McHale & Bellinger, 1988; Forrester, Murphy, Price & Monaghan, 1990) using the Critical Care Family Needs Inventory. These studies not only looked at congruence but also at differences between nurses' and family members' rating of the importance of family concerns (Norris & Grove, 1986; Lynn-McHale & Bellinger, 1988; Forrester, Murphy, Price & Monaghan, 1990).

In a study of 55 family members and 20 nurses, Norris and Grove (1986) reported that three needs were perceived to be significantly more important by families than by nurses. These needs included: to feel that there is hope, to know types of staff taking care of patients, and to have questions answered honestly. Limitations of the study by Norris and Grove (1986) include the small sample size and failure to describe visiting practices and policies.

Lynn-McHale and Bellinger (1988) compared the level of family needs by adding the measurement of the satisfaction of family needs as perceived by 92 critical

care nurses and 52 family members of patients in two critical care units. These researchers grouped family needs items into six categories: personal support, visiting, information, psychological support, the environment, and institutional support services. The study results indicated that family members were fairly satisfied with needs that dealt with personal support, visiting, and information. However, family members were less satisfied with needs pertaining to psychological support, the environment, and institutional support services. These researchers identified a large number of discrepancies between nurse and family member perceptions of whether or not family needs were met. Limitations of the study include convenience sampling, construct validity of the instrument was not reported, visiting policies and practices were not described and patient diagnoses were not identified.

Forrester, et al. (1990) studied 92 family members of intensive care unit (ICU) patients and 49 ICU nurses and reported significant differences between family members' perceptions and ICU nurses' assessments of the importance of 50% of the 30 needs examined. As well, nurses' ratings of the importance of family needs were consistently lower than family members. Limitations of the study include the use of a convenience sample and use of the CCFNI which lacks a family-derived theoretical basis.

All three studies of congruence between nurses and family member perceptions demonstrated differences between nurses and family member perceptions of the importance of family needs. Although these findings apply to an ICU setting and the diagnoses of patients were not documented, the lack of congruence may also be relevant to particular patient populations such as chronic heart failure patients and their families. As well, no studies were found that incorporated the patient's

perspective. The patient is a member of the family system and as such should be included in any assessment of family needs. Nor were any studies found that compared patients' perspective with family members' or nurses' perceptions of family needs.

Supportive Nursing Care

There are frequent references in the literature suggesting that part of the role of the nurse is to provide support to patients and their families. Indeed some authors (Simpson, 1989; Lynn-McHale & Bellinger, 1988) have organised items in the CCFNI into categories and have labelled at least two of these categories using the word support. However, precisely what is meant by supportive nursing care is not theoretically articulated. Although the dictionary defines support using words such as help, assistance, aid, succour, advocacy, relief, and sustenance, the exact meaning attributed to supportive nursing care remains somewhat elusive.

Whyte (1994) examined the notion of support in her study of the impact of cystic fibrosis on the family. As part of her work she asked families what support networks they used and also what support they would like to have. Whyte (1994) reported that parents found the following actions were deemed supportive: giving information, explaining investigations, answering questions, listening, providing a link between clinic, home, and school, and providing help with child care. Lugton (1994) carried out a study of what she described as formal and informal support of breast cancer patients. In her study, formal support referred to the professional support offered to patients and informal support referred to the informal social network used by breast cancer patients. In my study, the aim was to expand nursing knowledge

about the kinds of support family members wanted from nurses as well as to identify the kinds of support nurses saw themselves as providing.

In her study, Hentinen (1983) asked 59 wives from whom they received support during their husband's hospitalisation for myocardial infarction. There is no detailed information provided concerning the questionnaire used and validity and reliability are not reported. The questions seem to be dichotomous and focus on a list of symptoms of stress and a list of information received pertaining to in-hospital and at-home care. Wives were then asked what information they would have liked in hospital and at home. Theoretically stress is defined within the context of Lazarus' stress and coping theory and Selje's theory of stress. Support is repeatedly mentioned but never explicitly, theoretically defined. There are vague allusions linking support to coping, to information giving, and to social support. On inspection of the data presented in a table, support seems to refer to providers of support. Subjects were given a mixed list of lay people and health care professionals and asked to indicate whether or not these individuals provided support. One of the relevant findings indicated that wives wanted information and support regarding their husband's at-home care. Study findings are limited by the small convenience sample, the lack of information concerning precise contents of the questionnaire, and lack of clear theoretical definitions.

Thompson's (1989) study of sixty myocardial infarction (MI) patients and their partners can be seen to have some relevance for Chronic Heart Failure patients and their families. Thompson (1989) considered the concept of support in a study of the effects of supportive educative counselling on anxiety and depression in first-time myocardial infarction (MI) patients and their partners. Sixty couples were randomly

assigned either to an experimental or control group. The experimental group received supportive educative counselling while the control group received standard coronary care unit (CCU) care. Supportive educative counselling consisted of a programme developed from findings of studies in the literature that suggested anxiety and depression are common in MI patients and their partners. Furthermore, the literature indicated that these emotions can be negatively affected by lack of information, misunderstandings about the condition and expectations about recovery and resumption of physical work, and sexual activity. Support is not theoretically defined by Thompson (1989), however, the supportive educative programme is described in detail. Couples were provided with structured support and education that dealt with the patient's illness and recuperation. Although the content was general, the individual needs of couples were also taken into account. Specific areas of supportive educative care included: 1) the patient's illness (symptom management, prevention of recurrence, CCU environment, rate of recovery and rehabilitation, transfer to the ward and length of hospital stay), 2) physical reactions to MI, 3) psychological support, 4) couple involvement in decision making about aspects of care, and 5) the provision of a friendly confidential ear. Anxiety and depression were measured at two points in time: 24 hours after admission to CCU and five days later.

Study findings revealed that the dependent variables of depression and anxiety were significantly lower in the experimental group for patients. As well, anxiety was significantly lower in the partners as compared to the control group. A limitation of Thompson's study is that support lacks a theoretical definition. Supportive educative counselling seems to be a mixture of information giving and psychological counselling for both partners that has been derived from the literature. It is unclear how often

counselling sessions occurred or whether sessions were always conducted with both partners present. Supportive educative care, as he described it, does not deal with the limitations imposed by chronic cardiac illness outlined by Strauss, et al. (1984) such as social isolation, multiple problems of day to day living and financial concerns. Both the Hentinen (1983) and the Thompson (1989) studies dealt with acute illness situations and neither adequately theoretically defined what is meant by support.

Summary

The majority of nursing research pertaining to the family in the hospital setting has centred on acute illness and concentrated on family requirements for supportive care as family needs that were defined by nurses. Little has been done concerning the family in a chronic cardiovascular illness situation and much of the work done to date is limited because of the lack of a family-derived theoretical basis. The study of family in a chronic illness situation raises questions about the definition of family particularly in today's western society where traditional and legal definitions no longer suffice. In addition questions are raised as to whether or not the family can be studied as a whole through individual members. In essence the literature review dealt with the ill individual and the family who are living with and managing a chronic cardiac illness. The review presented the argument that there is a need to discover how nurses can help these ill individuals and their families effectively manage chronic cardiac illness both in acute episodes and on a day to day basis. There is a need to understand what supportive nursing care patients and their families want from their nurses and what supportive care nurses see themselves as providing. The few studies done concerning

supportive nursing care reveal lack of clarity about what is meant by supportive nursing care. Specifically, little is known about the supportive nursing care wanted by families caring for an individual with chronic heart failure either in the hospital setting or at home following hospital discharge. Furthermore, although the term supportive care is frequently referred to in the context of the family needs research done in the acute care setting, what is meant by supportive care is not explicitly or theoretically defined. There is a gap in knowledge concerning how supportive nursing care is theoretically defined, what kind of supportive nursing care nurses provide, and what kind of supportive nursing care families and patients want from nurses in a chronic cardiac illness situation.

CHAPTER 3

STUDY METHOD

Research Aim

The research aim was to explore patient, family and nurse perceptions of the supportive nursing care provided by nurses to patients and their families during acute episodes of chronic heart failure and on a day to day basis at home.

Research Purpose

The research purpose was to gain knowledge that would advance understanding of supportive nursing care. Furthermore, it was proposed that the knowledge gained would contribute to a family-derived theoretical basis for family nursing.

Research Questions

1. How do patients and their families describe supportive nursing care in the acute phase of a chronic cardiac illness?
2. What kind of supportive nursing care do patients and their families want from the nurses to help them to manage chronic cardiovascular illness in hospital and at home?
3. What are nurses' perceptions of the supportive nursing care they provide to patients and their families during the acute phase of a chronic cardiovascular illness?
4. How do nurses describe supportive nursing care for patients and their families after hospital discharge?

Theoretical Underpinnings for the Study

Chronic illness and family were the conceptual threads derived from the literature review that informed the underlying structure for the research approach. Aspects of managing chronic illness as described by Strauss and colleagues (1984) combined with elements from the family work of Wright and Leahey (1987, 1994) informed the interview schedule of this study.

Chronic illness

Chronic illness as described by Strauss, et al. (1984) and Thomas (1984) has been detailed in the literature review (Chapter 2). These theoretical viewpoints were suitable because they focus on the work of patients and their families in the context of chronic illness.

Family

For the purposes of my study, family was viewed as central to the care of the chronically ill patient. As described in the literature review, the family was seen as more than context for the ill patient; it was also a system comprised of individuals in interaction with each other and with the surrounding environment (Friedemann, 1989). Accordingly, the criteria used to identify family informants in my study were based on the commitment exemplified by Gilgun's definition of family and further elucidated by Stuart (Chapter 2, p. 23). The criteria included:

- family consists of a group of individuals committed to each other over time
- family has caregiving functions
- access to the family is gained through the patient and consists of mutually defined members
- family is made up of individuals in interaction with each other and with

their environment

Supportive Nursing Care

Supportive nursing care for the purposes of the study was considered within the context of Fawcett's (1983) nursing metaparadigm and was informed by general systems theory and symbolic interactionism as described in Chapter 2.

Methods of Study

Methodological Approach

A qualitative approach was used to answer the research questions because this method seemed most appropriate. The use of a qualitative research approach as a valid way to study a research problem is well recognised in the literature today. Qualitative research is appropriate when the purpose of research is to try to understand human experience from the perspective of the participants in the setting being studied (Field & Morse, 1985). It is also an appropriate approach when theory construction is proposed (Field & Morse, 1985; Glaser & Strauss, 1967). Thus, congruence with the purpose of my proposed study is evident.

Qualitative Research

Miles and Huberman (1994) described the rapid expansion of qualitative research over the past 10 years as being "phenomenal" (p.1). Various authors have identified a wide range of qualitative research traditions. Marshall and Rossman (1989) included ethnography, cognitive anthropology, and symbolic interactionism as qualitative research approaches. Smith (1992) added field methods, qualitative inquiry, participant observation, case study, and naturalistic methods to this list. Numerous recent books on the topic of qualitative inquiry testify both to the wide

range (Denzin & Lincoln, 1994) and to the raging epistemological issues (Guba, 1990) characterised in the literature.

Wolcott (1994) and others (Denzin & Lincoln, 1994) concurred that qualitative research is committed to the naturalistic perspective and to the interpretive understanding of human experience. A naturalistic perspective refers to the "preference for 'natural' settings as the primary source of data" (Hammersley & Atkinson, 1983, p.6). Interpretive understanding of human experience refers to the subjective understanding of others in a social situation. According to Miles and Huberman (1994) "the paradigms for conducting social research seem to be shifting beneath our feet" (p.5). It no longer seems relevant to position post positivism and interpretivism in bipolar opposition or indeed to argue the merits of one over the other. Post positivists employ naturalistic approaches and ethnographers use pre-designed conceptual frames and instruments (Miles & Huberman, 1994). There is no longer the need to explicate and justify an interpretive naturalist approach to investigating a research problem or focus.

Qualitative research may be carried out through intense contact with a group or setting. The researcher attempts to capture data on the perceptions of individuals and to interpret the ways people in particular settings understand, account for, take action, and manage day to day events (Miles & Huberman, 1994). This approach seemed compatible with my study because I wanted to understand patient and family member perceptions of supportive nursing care within the context of a chronic heart failure illness situation. Furthermore, I wanted to do so during an acute episode of illness and on a day to day basis.

A qualitative approach can be used to generate and revise theory (Miles &

Huberman, 1994; Glaser & Strauss, 1967). Furthermore, the data generated from a qualitative approach can yield new ways of integrating ideas and concepts. One of the intents of my study was to contribute to a family-derived theoretical basis for family nursing. I wanted to acquire the knowledge needed to contribute to a theoretical basis for supportive nursing care and to explore whether or not family could be studied as a whole through individual members. Using an ethnographic qualitative approach seemed the most appropriate way to accomplish this.

Method

Thorne (1991) suggested that nursing needs to develop its own qualitative methodology which may incorporate aspects of different approaches such as ethnography, grounded theory, and phenomenology. The method I used was influenced by ethnography for the interviewing process for data collection combined with a comparative analysis approach from grounded theory for data analysis.

Ethnography has been strongly linked to interactionism with a focus on understanding meanings (Silverman, 1993, p. 23). The process of understanding meanings is accomplished through:

- extensive contact with a particular group or setting
- study of day to day life
- emphasis on description
- focus on the individual's perspectives and interpretations, with unstructured data collection
- a variety of ways of capturing data such as audio tapes, observation and videotapes (Hammersley, 1990)

Miles and Huberman (1994) challenged the notion put forth by Hammersley

(1990) who suggested that ethnographic data collection is unstructured. I concur with Miles and Huberman (1994) and used a semi-structured approach to my interviews. I chose this course of action since, although not well understood, there is some understanding of the constructs of chronic illness, the family, and supportive nursing care. Clearly, not enough was known about these concepts to develop a theory. Miles and Huberman (1994) contended that we need both inductive and deductive approaches to data collection and analysis to bring together findings into a "coherent set of generalizations". Strauss (1987) also suggested that analysis is grounded in the data and that data collection and analysis involves induction and deduction. By induction Strauss (1987) means that a hunch or idea comes from the data and is converted into a hypothesis by the investigator. He further stated that deduction is the "drawing of implications from hypotheses for purposes of verification" (p. 12). Verification is determining whether the hunch or idea hypothesised is "total, partial or negated" (p. 12). Induction, deduction, and verification continue throughout the research and are not simply sequential. My purpose was to contribute to a family-derived theoretical basis for family nursing. A qualitative descriptive approach allowed me to understand what kinds of supportive nursing care patients and their families wanted from nurses in a chronic heart failure illness situation.

Issues Concerning Method

Some issues relevant to my study include validity, reflexivity, replicability, and generalisation. A discussion of each issue follows.

Validity

Validity in the classical scientific sense is a term that many qualitative

researchers consider not to be applicable to the assessment of qualitative research (Silverman, 1993). According to Hammersley (1990) in the traditional scientific sense validity means “truth: interpreted as the extent to which an account accurately represents the social phenomena to which it refers” (p. 57). He further stated that in the traditional scientific sense a true statement involves two kinds of error. Type 1 involves believing a statement to be true when it is not and type 2 involves believing a statement to be false when it is actually true. Alternatives to validity, such as trustworthiness have been proposed (Lincoln & Guba, 1985). Trustworthiness as first described by Lincoln and Guba (1985) referred to the researcher’s responsibility of displaying the process used to collect and analyse data to arrive at an interpretation of the meaning informants ascribe to an experience. Researchers such as Hammersley (1990) contend that there is no single truth and hence seeking to validate truth is inappropriate. Instead, the researcher is obliged to provide sufficient information about the collection and analysis processes used by the researcher so that the reader can make a judgement about the trustworthiness of the conclusions drawn by the researcher. This approach involves critiquing of the process for attributes such as credibility and believability. It is the responsibility of the reader to be knowledgeable enough of the process and the topic under study to be able to make such a judgement. The onus is on the researcher to lay bare the process in sufficient detail to allow for such critique. Reflexivity is part of the way that the researcher establishes credibility.

Reflexivity

Qualitative researchers view reality as a social construction and recognise the reflexive nature of the relationship between the researcher and what is being studied. Reflexivity refers to the fact that the researcher is an inextricable part of the setting,

the context, and the culture he/she is attempting to understand and interpret. Validity is viewed as reflexive accounting that essentially means that the focus is on careful description of the process of ethnographic work. Reflexive accounting involves careful delineation of the ethnographic process including accounts of interactions among context, researcher, methods, setting, and informants (Altheide & Johnson, 1994). Detailed accounts of problems of communication with informants, misinformation, evasion, fronts, taken for granted meanings, problematic meanings, and self-deceptions must be incorporated into the reporting of qualitative research as a way of validating the research process.

Atkinson (1992) placed the onus on the researcher to provide sufficient information on the process of knowing. He stressed the importance of clear and precise articulation of how we claim to know what we know. If you believe that there are multiple realities (relativist ontology), that the researcher and subject under study together create understanding (subjective epistemology), and that this occurs in a naturalistic setting, then credibility, transferability, dependability, and confirmability replace validity and reliability. Trustworthiness of the process by which interpretations are made becomes a cornerstone of the legitimacy of any claims made (Lincoln & Guba, 1985).

The purpose of conducting qualitative research is to uncover meaning. Many meanings can be attributed to data. Traditional ways of viewing validity are not compatible with a qualitative approach. Authors like Mishler (1990), Hammersley (1990), Atkinson (1992), and Lincoln and Guba (1985) concur that the reader of research makes judgements about the "trustworthiness" of research study findings. The reader is obliged to critique the process used by the researcher in order to make a



judgement about whether or not the findings can be used or built upon. In order to make this judgement, sufficient information about the process used to collect and analyse the data must be provided in the research report. Lincoln and Guba (1985) coined the term "trustworthiness" to replace use of the traditional term validity. They defined trustworthiness in terms of examination of the process used to collect and analyse data previously mentioned. Mishler (1990) has expanded upon their definition by going a step further and suggesting that chosen qualitative studies be used as exemplars of excellence against which other works can then be compared.

Replication

Sandelowski (1993) would argue that reliability in terms of replication is not an appropriate expectation in qualitative research while other authors like Miles and Huberman (1994) consider replication of qualitative work to be possible. The overriding argument is not whether or not a phenomenon can be replicated but whether or not it is appropriate to think that it could or should be replicated. If two researchers hold the same epistemological perspective then the way they interpret the same data may well be similar.

Generalisation

Qualitative research has been criticised for being non-useful because the findings cannot be generalised (Lincoln & Guba, 1985). This assertion was based on the usual interpretation of generalisation as being derived from data representative of a population. However, proponents of qualitative research have suggested that generalisations are not made to populations but rather to theory (Yin, 1989; Hammersley, 1990) and hence the criteria of representation do not apply. However, uncertainties remain concerning the argument that qualitative researchers are not

attempting to generalise to populations but rather to theory. After all, as Hammersley (1990) has noted, generalising is generalising whether to theory or to population.

Generalisation was a topic of relevance to my work since one of the intents of my work was to generate theory. Hence, it would seem relevant to raise and discuss generalisation within the context of naturalistic inquiry. It is a challenge to discuss generalisation because one of the basic elements of naturalistic inquiry is to preserve the unique, the unusual, and to highlight and understand that which is different. The categorisation or grouping of data is a step in the qualitative analytic process that leads the researcher to make generalisations. In a grounded theory approach to data analysis this generalisation is to theory. Some qualitative researchers have critiqued the categorisation of data as a fragmentation that results in loss of meaning.

One answer to the fragmentation of qualitative data through categorisation and the possible loss of that which is unique is to adopt a narrative, story-telling approach to data analysis and the generation of interpretive theory (Atkinson, 1992). Yet, proponents of this approach (Atkinson, 1992; Denzin & Lincoln, 1994) repeatedly stress the "local" nature of interpretive theory. In other words, theory is constrained by space and time. One cannot generalise beyond the local situation. Hence, this narrative approach to data analysis was not helpful to the purpose of my study.

A comparative analysis approach to data analysis seemed more congruent with my purpose of generating theory that has potential for use beyond the local situation. The generation of theory suggests the grouping of commonalities amongst data, and the categorisation and linking of concepts which in qualitative research can be accomplished through the use of constant comparative analysis (Glaser & Strauss,

1967). Comparative analysis or grounded theory analysis is a particular way of analysing data that is meant to both generate and test theory (Strauss, 1987). Hence, a constant comparative analysis approach to data analysis was used in my study.

Summary

In summary, a qualitative research approach provides a method for understanding human experience from the perspective of the participants in a natural setting. Furthermore, the use of comparative analysis is appropriate when theory construction is proposed. Specifically the preceding discussion has shown that a qualitative research approach and the use of constant comparative analysis suited my research aim and purpose. The aim was to explore patient, family and nurse perceptions of the supportive nursing care during acute episodes of chronic heart failure as well as on a day to day basis at home. The purpose was the acquisition of knowledge to advance understanding of supportive nursing care and contribute to a family-derived theoretical basis for family nursing.

CHAPTER 4

STUDY PROTOCOL AND ANALYTIC FRAMEWORK

In the following chapter, I will describe the study setting, participants, ethical procedures, and data collection. The analytic framework that was developed and used to analyse the data will then be described and a detailed account of how the framework was applied will be provided.

Setting

The study was carried out in a small city of 160,000 thousand people in Northern Ontario, Canada. Data were collected in three settings, two local acute care hospitals and a cardiac rehabilitation centre. The hospital settings were chosen because they were the cardiovascular and emergency referral centers for the region and thus allowed access to patients and their families during an acute episode of chronic heart failure. The cardiac rehabilitation centre was chosen because it allowed access to patients and their families experiencing chronic heart failure on a day to day basis.

Study Participants

The study participants included family units comprised of an individual hospitalised with an acute recurrence of chronic heart failure (CHF), the primary caregiver within the family, one other family member, and nurses caring for the hospitalised individual (Table 1, Table 2, Appendix A). Over the five month data collection period (May, 1996-October, 1996), the emergency department nurse manager, the intensive care unit (ICU) nurse manager, and later the cardiac rehabilitation nurse were telephoned on a daily basis. These individuals assisted in

identifying potential candidates eligible for the study, ie. hospitalised with an acute episode of chronic heart failure or newly admitted to the rehabilitation programme. The charts of each potential patient participant were reviewed to determine whether these individuals met the study inclusion criteria of having had at least one previous episode of congestive heart failure that required hospitalisation, and were currently either hospitalised or enrolled in a cardiac rehabilitation programme. Patients who met these criteria were approached and asked to participate in the study. Those patients who were deemed by the ICU nurse manager as too ill to be interviewed were approached once their health status had stabilised (Mrs. Pageau, Mrs. Roy, and Mrs. Moore). Although, Mrs. Moore was identified while in the ICU she was only well enough to be interviewed when she began the rehabilitation programme.

The study aim was explained to each potential study participant using a standard study explanation (Ethics Documents, Appendix B). If potential candidates agreed to participate in the study, they were then asked to identify two family members who were involved in their care and who might be willing to participate in the study. Family members were then approached, given a brief explanation of the study and asked if they would be willing to participate. After obtaining informed consents, patient informants were also asked to identify a nurse who they felt had provided supportive nursing care to them during their current hospitalisation. Nurse informants were then approached and invited to participate in the study and nurse informant consents were obtained (Ethics Documents, Appendix B).

Four of the eleven patients interviewed were able to identify a particular nurse as supportive. One of these patients was in the intensive care unit when

interviewed, one was hospitalised on a medical floor, and two were participants in the cardiac rehabilitation programme. In the seven cases where patients were unable to identify a particular nurse as supportive, I interviewed the nurse who had cared for the patient that day. One of these seven patients was in ICU, one was in the rehabilitation programme, and the remaining patients were on the floor.

Patients and family members gave reasons for not being able to identify a particular nurse as supportive such as, being unable to single out a particular nurse because all the nurses were “good”. Other patients said that a nurse in ICU was supportive because she kept them alive. However, they could not remember the ICU nurse’s name when I interviewed them after they had been transferred to the floor. Consequently, I was unable to accurately determine who these nurses were. Three patients and their family members could not identify a nurse who was supportive and instead gave accounts of nurses who they felt were not supportive in order to highlight what they thought being supportive meant.

Only English speaking individuals were recruited into the study, in order to ensure that data would be suitable for qualitative analysis. Families asked to participate in the study were typical families who have a member with CHF (Chenitz & Swanson; Hammersley & Atkinson, 1995; Spradley, 1980). Families were typical with respect to the traditional definition of family which is being blood kin and/or living in the same household (Gelles, 1995). Every family was comprised of ‘blood kin’ and most lived in the same household. New family units and nurses were recruited into the study until the point of data saturation. Data saturation occurred when information being shared became repetitive.

In total 11 patients, 11 primary caregivers, 9 other family members, 8 family units and 11 nurses were interviewed (Table 1, Appendix A). One additional family unit was interviewed at the beginning of the study however the tape recorder was faulty making the interviews unusable. Hence, the data from this family unit were not included in the study. Seven of the patients were females and four were males. They ranged in age from 50 to 77 years of age, six were married, four were widows (two recent) and one was a widower. Seven lived with their family, two lived alone, and one lived in a residential home. In five of the family units, the primary caregiver was the spouse while in four others the daughter was the primary caregiver. In one family unit, a son was the primary caregiver and in the remaining family unit, the patient and his spouse both described the patient as his own caregiver. The second family member was a son, daughter, or daughter-in-law. The families who participated in the study were generally typical of this patient chronic heart failure population having experienced at least one previous acute episode of their chronic heart disease that required hospitalisation.

Seven patient participants were sampled in a hospital setting (on the floor and in ICU) and four were sampled from a cardiac rehabilitation programme. This was done in an attempt to capture both acute episodes and day to day living with chronic heart failure. The goal of sampling from these different settings being to more fully develop and link emerging categories in the theory. Patients, their families, and nurses were selected from the cardiac rehabilitation programme for theoretical purposes and relevance to develop emerging categories since the scope of a “substantive theory can be carefully increased and controlled by such conscious choice of groups” (Glaser & Strauss, 1967). The cardiac rehabilitation patients

recruited to the study were new admissions to the programme. Patients were normally admitted to the rehabilitation programme two weeks after being discharged from the hospital. All but one of the four patients had enrolled in the cardiac rehabilitation programme two weeks after being discharged from the hospital. Three of these patients (Mrs. Moore, Mrs. Valenti, and Mrs. Levesque) had long histories of heart failure while the remaining patient had been hospitalised once during the previous six months (Table 1, Appendix A).

Ethical Considerations

Informed consent to participate was obtained from all study participants as outlined in Appendix B (Ethics Documents). Study participants were given an explanation of the study and the procedures to be followed. Participants were assured that there was no risk to their health and that they could withdraw from the study at any time or refuse to answer any questions without jeopardising care. Prospective participants were encouraged to ask questions about the study. Privacy was ensured by approaching potential participants in a secluded setting, at the bedside, in the hospital family room or in the family dwelling. Participants were asked for their permission to tape record interviews and were informed that these tapes would be destroyed on conclusion of the study. Data was stored in a locked cabinet accessed only by the researcher. Participants were informed that the findings would contain participant quotations, however, these would be anonymous. Participants were told that information gained from interviews might be published, however, participant names would not be revealed. They were also told that a report of study findings would be made available to all participants at the end of the study. Since family members and patients were interviewed separately prior to the family

unit interview, it was important to indicate to each informant that information conveyed to myself was private and confidential and would not be divulged in the group interview. The institutions in which data were collected were informed that they would not be named in any publication unless permission was given to do so. Ethical approval was sought and obtained from the university and hospital ethical review committees prior to implementation of the study (See Appendix B, Ethical Documents).

Data Collection

The main data gathering strategy used in my study was in-depth interviews that were conducted individually with patients, two family members, and their nurses and then with the family unit. The Strauss et al. chronic illness framework and the Wright and Leahey family assessment framework (1994) were used to theoretically inform the structure of the interview process. The family assessment framework (family development, structure, and function) including a genogram was used to create the family profiles that are presented in Chapter 5.

In accordance with a grounded theory approach to data collection, a semi-structured interview guide was developed and evolved as the study proceeded (Table 4, Appendix A). The interview guide contained general and probing questions related to specific issues such as the management of cardiac illness, how the patient came to the hospital, and what changes arose with illness. As the interviews progressed, the interview questions were modified according to the concepts and trends that emerged from the data. Eventually the interview questions were formulated to contain and reflect the content of previous informants' words and to further explore and clarify emerging categories. The interview questions were

derived from the literature (Strauss, et al. and Wright & Leahey) and the content of participants' words. Relevant socio-demographic data for each informant were collected. Relevant socio-demographic data for patients included age, length of hospital stay, number of previous hospitalisations for chronic heart failure, and for relatives, age and for nurses, age and years of work experience.

Interviews

All patients, two family members and their nurses were interviewed once, privately on an individual basis. Patients who had been hospitalised were interviewed with their families as a family unit at the patient's home four to six weeks after being discharged from hospital. This post discharge time frame was chosen because Gilliss (1984) determined, in her study of post coronary artery bypass graft patients, that up until six weeks, was a critical time for the family in adjusting to management of recovery. Patients and family members selected from the cardiac rehabilitation programme were interviewed at their homes on an individual and then on a group basis.

In the hospital setting, patients and family members were interviewed for approximately 30 to 40 minutes. Interviews with family members and patients following discharge lasted from one to several hours depending upon the patient and family member. No interviews were terminated as a result of patient fatigue or stress. Nurse informants were interviewed once in their clinical practice area for approximately 30 minutes. All interviews were taped and transcribed and observations were recorded as field notes (LoBiondo, Wood, & Haber, 1998).

Field Observations

Field observations were written in a systematic format and interviews were

transcribed as soon as possible after each interview. In an ongoing interactive process as the data were collected, observations were recorded in field notes, method and analytic field notes or memos were written, and connections with relevant literature made. Analytic field notes (Hammersely & Atkinson, 1983) are similar to theoretical memos described by Glaser (1978). Through ongoing reflection and review of field notes and transcribed interviews, the research process gradually became focused.

Field notes or memos were recorded as three types: substantive, methodological and analytic (Burgess, 1984). Substantive field notes consisted of a continuous record of situations, events, and conversations. These field notes provide a detailed portrait of the various interview situations and contain physical descriptions of situations and informants, details of conversations that have not been taped and accounts of events. They record such things as, voice emphasis, tone, strength, loudness, rises/falls at the end of sentences, use of eye contact, facial expression, and body language such as the use of hands/arms, turning towards or away from individuals.

I kept methodological field notes to record personal reflections on activities in the field—problems, impressions, feelings, and hunches. This type of field note was used for reflection and self-analysis. Analytic field notes were used for recording preliminary analyses worked out in the field. A continual series of theoretical memos or analytic field notes were written and used throughout the analysis process. In these memos, I recorded theoretical questions and summaries. They also served as a way of chronicling the coding of categories and of prompting more coding and ultimately helped to consolidate thinking. As the data collection

moved to the final stages, analytic or theoretical memos became more complex and detailed. At this point, they were used to sort or pull together ideas expressed in earlier memos and helped to integrate the evolving theory. Glaser (1978) calls this theoretical sorting and suggests that this process is the sorting of ideas that have been recorded in theoretical memos. Sorting forced the identification of connections between categories and integrated relevant literature. The literature was used to explain phenomena seen in the field and to help clarify ideas, to draw comparisons, and look for similarities and differences. Existing theory or theories were used to explain and analyse data (Hammersley & Atkinson, 1983).

Data Analysis

Analysis happened simultaneously with the data collection process as information about chronic heart failure and the family experience was absorbed and integrated. Initially, many ideas and topics emerged as field notes were written and tapes of interviews transcribed. Taped interviews with the patient, family members, the nurse and the family unit were transcribed and the transcripts carefully reviewed many times to ensure thorough familiarity with the data. At this phase of the data analysis, the intent was to think with the data (Hammersley & Atkinson, 1983, p. 178). Constant questioning, concept analysis, and systematic comparisons were used to encourage theoretical sensitivity. The auditability of the study was defined by systematic, detailed and accurately transcribed interviews, memos and recorded analysis.

Transcription

Transcription is the first step in the data analysis process. The process of transcription of the audio taped interviews is a process whereby the content of the recorded interviews was converted from oral to written format. Qualitative researchers acknowledge that creating written text from recorded interviews is critical to the success and quality of the analytic process (Silverman, 1993). Quality of the transcript process is important because a standard approach allows for alternate interpretations of the data by readers. This approach in my study involved capturing aspects of the oral recordings, such as pitch, pauses, and tone of voice. In fact, transcription is the first critical part of the analytic process (Table 3, Appendix A).

Review and reflection of the interviews following transcription led to the identification of categories which then guided the direction and questions of subsequent interviews—Glaser (1978) referred to this process as theoretical sampling. Hammersley & Atkinson (1983) identified a similar process whereby the research gradually becomes focused through continual ongoing analysis of the data while it is being collected. This process of continued reflection allows the researcher to describe what is happening but can also allow the researcher to move beyond description to the development and testing of explanations.

Concept Generation

Concepts were generated by looking for patterns and by looking for anything unusual or puzzling in the data. As well, the data were examined for congruence with pertinent existing theories, literature, and experience. The data were studied for inconsistencies and/or contradictions amongst types of informants (nurse, patient,

family member) and discrepancies between the stated beliefs and actual behaviors of participants. Concepts and ideas were noted in the margins of transcripts and field notes.

Identified concepts were given labels taken from other literature (uncertainty) and new terms (family responsibility) were created. Concepts were generated by asking questions of the data and by using theoretical sampling and comparative analysis. These two latter concepts are inter-related. Theoretical sampling is directed by the evolving theory and involves the sampling of incidents, events, activities, and populations to then make comparisons among them. When one or two analytic categories emerged, the next task was to develop these into a theoretical scheme by looking for links or connection between concepts (Hammersley & Atkinson, 1983). At this point the Glaser and Strauss (1967) strategy of comparative analysis was useful. This process allowed the examination of each piece of data and after considering its relevance to emergent categories, to compare it to other pieces of data that were similarly categorised. Thus the scope and variation of a category were delineated and patterns in relation to other categories were identified. A clearer picture of how concepts related to each other was realised through this process.

Categorisation of concepts is not only grounded in the study data but also in the experiential data (the knowledge of relevant literature that the researcher brings to the study). This combination of data generated by the study itself and experiential data helped in thinking about concepts and their linkages. Gradually through continued reflection, theoretical sampling, and comparative analysis the main concerns or issues were identified.

The ethnographer can describe social events and processes or move beyond to developing and testing explanations (Hammersley & Atkinson, 1983, p. 175). The development of explanations can be the outcome of theoretical sorting which occurs in the final stages of data collection as has been described earlier in the data collection section of this chapter (Glaser, 1978). Theoretical sorting refers not to the sorting of data but rather to the sorting of conceptual thinking that has been captured in analytic/theoretical memos recorded by the researcher throughout the data collection, categorisation, and analysis process. According to Glaser (1978) the sorting of ideas contained in analytic memos leads directly to the writing up phase. The aim is to develop a theoretical explanation of what is happening in the data. The analytic framework that was developed for my study is described in the following section of this chapter.

Analytic Framework

A detailed description and application of the analytic process used to analyse the study data is presented here to demonstrate how the two major concepts of uncertainty and family responsibility emerged from the data. Then, how the definition of supportive nursing care was developed from the interview data will be illustrated.

In brief, the process involved:

- Open coding (naming of substantive categories with words taken directly from the data)
- Ongoing category identification, memo writing, and category integration
- Looking for connections and linkages between substantive categories

- Moving substantive categories to the conceptual or theoretical level
- Delineating properties, conditions and consequences to further develop the concept.

As the data were collected the process of open coding was used resulting in the identification of a number of categories in the patient and family accounts of their experiences. These categories included “not knowing”, “not understanding”, and being “unsure” about what symptoms meant; not knowing whether or not to go to the hospital when symptoms occurred; and not knowing what to expect in the future. During open coding, categories were named with words taken directly from the data. These categories were then used for exploration in interviews with subsequent patients, family members, and nurses. Throughout data collection the grounded theorist questions the data and begins to develop theoretical ideas about what is emerging from the data. Hunches and ideas that were found in the data were explored by gathering more data to further expand developing categories.

Being unsure or uncertain about the cause of symptoms and hence not knowing whether to call the ambulance was identified as a problem or concern for the first patient, Mrs. Roy. This finding raised questions about what her family members would report about the events that led to her hospitalisation. As well, I wanted to know what the nurse would recount about the supportive care she thought Mrs. Roy and her family needed. So, descriptions of what happened prior to her hospitalisation that had been elicited from family members were analysed to determine how decisions to go to the hospital were made and to see whether descriptions of uncertainty arose. Descriptions obtained from Mrs. Roy’s nurse and subsequent patients, their families and nurses were similarly analysed. Coding, memoing, integrating, and writing up of ‘not knowing’ or ‘not understanding’

symptoms forced me to focus and to look for connections and linkages with other codes in the data and to identify these as subcategories of uncertainty.

The same process was used to develop 'not knowing what to expect after discharge from the hospital' and 'not knowing when or how death would happen' as subcategories of uncertainty. Uncertainty was the label that I eventually attached to a group of substantive categories that dealt with different topics or events but that seemed to fit together.

Substantive categories are less abstract than conceptual categories. Shifting from a substantive to a conceptual level means treating the code as a conceptual category rather than as a descriptive topic or word. According to Glaser (1978) one way to develop a conceptual category from a substantive category is to determine whether the substantive category is a property, condition, or consequence. Another strategy is to identify how a conceptual category changes, and how it relates to other categories. Identification of categories as properties, conditions, and consequences helped to develop the conceptual categories that emerged from the data.

Properties are essentially qualities or characteristics or attributes and conditions are the circumstances under which each category occurs while consequences are the effects of the relationships found in the data between categories. Identification of the properties, conditions, or consequences of substantive categories helped to develop the conceptual category uncertainty while at the same time ensuring that uncertainty was grounded in the data. For example, I asked the question, under what conditions did uncertainty occur in the data? It became apparent that uncertainty occurred in relation to not knowing about symptoms, which was linked to decision making about whether or not to go to the

hospital when acute illness events occurred. Uncertainty also occurred around expectations after discharge from the hospital and around the topic of dying.

Constant comparison and questioning of the data are analytic processes that allow the researcher to move substantive codes to the theoretical level. I used constant comparison to compare data with data, and category with category. In my study comparing data with data involved for example:

- 1) comparing different patient and family member accounts of how patients came to hospital, their understanding of patients' symptoms, and how they and their families handled issues around coming to hospital, being discharged and talk of when and how dying would happen;
- 2) comparing data from the patients and their family members at different times.

I used the following questions to examine the data to decide whether substantive codes could be identified as properties, conditions, or consequences of uncertainty:

- 1) What were ill patients and their families uncertain about?
- 2) At what time did uncertainty occur?
- 3) What were the consequences of it?
- 4) How did they handle it?
- 5) What factors, behaviors, activities precipitated uncertainty?

Through a similar analytic process, the conceptual category of family responsibility emerged from the data. I looked for links and connections amongst subcategories and further developed this conceptual category by asking questions of the data concerning properties, conditions, and consequences. I used constant comparison to compare data with data, and category with category. Comparing data

with data involved the comparison of different patient and family member behaviours and their accounts of family changes through the use of four questions:

- 1) What illness connected changes happened to patients and their families?
- 2) What conditions precipitated these changes?
- 3) How were decisions to make changes in patient and family living arrangements, roles, and activities made ?
- 4) What were the consequences of changes for patients and for their families?

The identification of properties, conditions, and consequences helped to develop the conceptual category family responsibility while at the same time ensured that family responsibility was grounded in the data. I used the following questions to examine the data to decide what the properties, conditions, or consequences of family responsibility were:

- 1) What were the characteristics of family responsibility?
- 2) Under what conditions did family responsibility occur?
- 3) What were the consequences of family responsibility?
- 4) What factors, behaviours, and actions contributed to family responsibility?

Supportive nursing care was a pre-determined concept that was further elucidated by the analysis of data gathered from each type of study participant. A collective definition was then derived from the responses of patients, their families and nurses to the question of what supportive nursing care meant to them. Categories were developed from the data gathered about supportive nursing care, links between

these categories were identified, and their subcategories delineated by asking the following questions of the data:

- 1) What did patients, families and nurses consider supportive nursing care to be?
- 2) What were the properties of supportive nursing care?
- 3) What conditions led to supportive nursing care?
- 4) What were the consequences of supportive nursing care for patients, families and their nurses?

Summary

The constant comparative method of analysis, a process whereby data are compared with data continuously as they are acquired during the study, was used (Glaser & Strauss, 1967). This analysis was utilised with theoretical sampling, data collection, and literature review. Through the processes of open coding and making connections amongst the cluster of categories, concepts were defined and relationships between concepts identified. Theoretical memos were written and assisted in refining categories. Identifying substantive categories as properties, conditions, or consequences helped to develop the conceptual categories of uncertainty and family responsibility while at the same time ensuring that these concepts were grounded in the data. A definition of a third pre-determined concept, supportive nursing care, was developed through an analysis of the properties, conditions, and consequences found in the patient, family member, and nurse interview data. The emergence and/or development of each of these concepts will be described in subsequent data analysis in chapters, 6, 7, and 8. Family profiles are presented in Chapter 5.

CHAPTER 5

FAMILY PROFILES

In introducing the family units, I have taken an approach that includes a description of the illness trajectory and an analysis of family based on the Calgary Assessment Model (C-FAM) to organise information. The names of families, occupations, and so on, are fictional to protect the anonymity of patients and their families. True anonymity, in which even the researcher cannot link the data with the study participant, was not possible within the research study framework. Family unit names appear throughout the remainder of the analysis and discussion chapters.

Each family profile begins with an overview of the patient and family illness trajectory (Strauss, et al. 1984) and includes a categorisation of patient illness according to Rolland's typology as described in Chapter 2. Then there is an analysis of family composition, context, function, and development based on Wright and Leahey 's (1984) Calgary Family Assessment Model (C-FAM).

C-FAM is a multi-dimensional framework for family assessment that has three main categories (structural, developmental, and functional). I chose this framework because the theoretical basis of C-FAM is compatible with symbolic interactionism and general systems theory (discussed in Chapter 2) and with the underlying structure for the research approach.

The structural category includes both internal and external components encompassing family composition, rank order, and subsystems. The developmental section refers to life stages through which the family progresses and the tasks that are characteristic of each stage, such as socialisation and attachment between family

members. The functional category may include elements such as, emotional communication, verbal communication, non-verbal communication, problem solving, roles, and beliefs (Wright & Leahey, 1984, p. 193).

The framework was helpful in analysing the way in which families interacted and nurtured development and function. A family genogram provides a summary of family composition or structure. The symbols used in the genograms are illustrated in Figure 1. On the following pages, the family profiles of the family units who participated in the study are displayed in figures 2 to 12. They portray an overview of the illness trajectory and family structure, function and development.

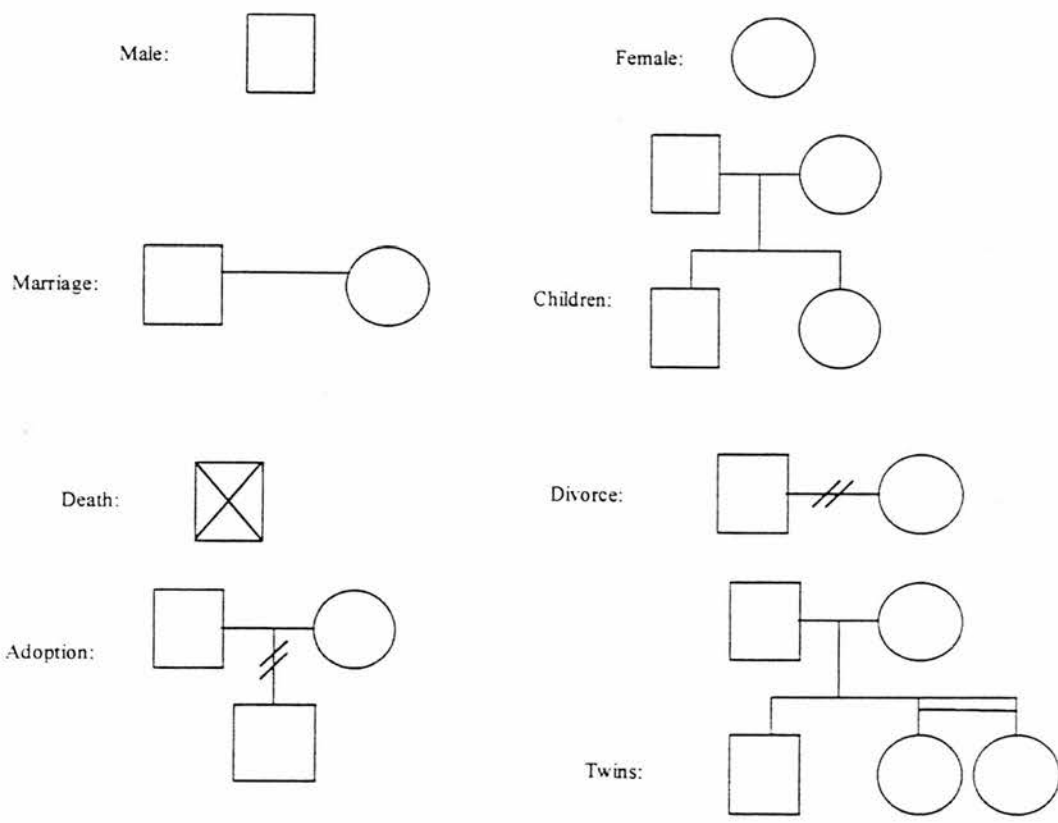
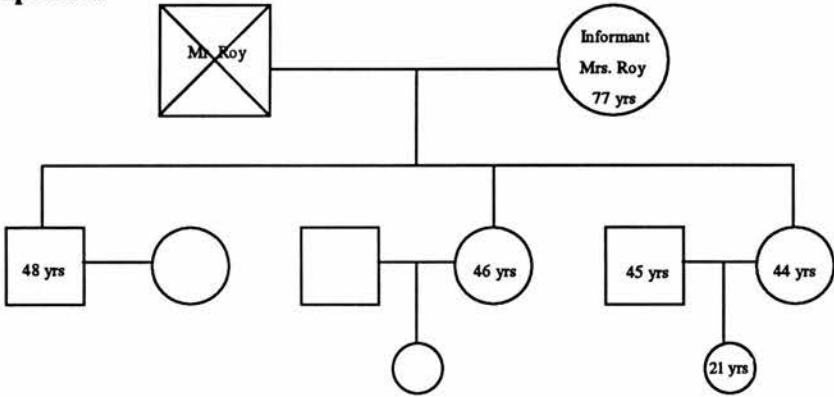


Figure 1. Genogram symbols.

Illness Trajectory

Mrs Roy has a long history of cardiac illness. She had her first heart attack when she was 61 years old. Three years ago she was hospitalised for heart failure and during the past 6 months she had been hospitalised three times for congestive heart failure. During each episode she spent time in the intensive care unit. The daughter with whom she lived had been told by the cardiologist that each episode had resulted in further destruction of her heart to the extent that she had a heart that functioned at 25% of normal capacity. Mrs. Roy is in the pre-terminal phase according to Rolland's typology.

Family Composition



Family Context

Mrs. Roy was a French Canadian, Roman Catholic who had a primary school education. She lived in a granny flat in the basement of her 44 year-old daughter's home. Her daughter worked as a secretary and her son-in-law worked as a labourer in the local industry.

Family Development

This family was in the process of adjusting to Mrs. Roy's deteriorating health and is in the family development stage of launching.

Family Function

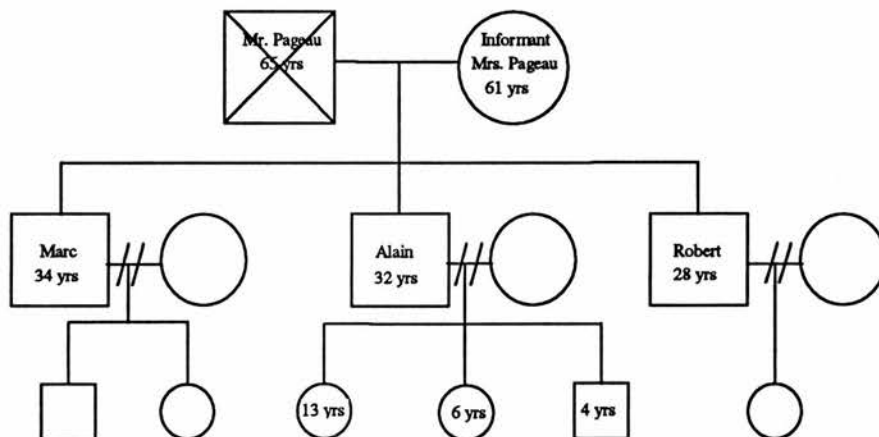
Functionally this family communicated their thoughts and feelings to a limited extent. Mrs. Roy's daughter had expressed her fears to me that Mrs. Roy would die however, she had not discussed these fears with Mrs. Roy. The daughter said she could talk with her sister but not with her brother. She felt her brother was very unrealistic about Mrs. Roy's care. Mrs. Roy appeared close to both her daughters and spoke affectionately of her grand daughter. The only household chore that Mrs. Roy was able to do involved preparing her own meals. Cleaning of her flat was done by a visiting homemaker. Mrs. Roy was responsible for taking her medication. Her daughter felt uncomfortable with how little she knew about Mrs. Roy's illness, especially the symptoms and treatment. The grand daughter had Crohn's disease that was under control at the time of interview. However, Mrs. Roy's daughter was very concerned about the impact of her mother's illness on her daughter.

Figure 2. The Roy Family Profile

Illness Trajectory

Mrs. Pageau, a 61 year old woman was brought to the emergency room of the hospital by her son, Alain. She was admitted to ICU with a diagnosis of congestive heart failure. She was intubated and remained in ICU for four days. Her diagnosis and prognosis were uncertain. According to Rolland's typology of chronic illness, Mrs. Pageau was in the crisis phase. Although she had a history of atrial fibrillation and mitral valve disease, this was the first time she had been hospitalised with life threatening heart failure.

Family Composition



Family Context

Mrs. Pageau was a French Canadian, non-practising Roman Catholic who had never been formally educated. Up until hospitalisation she had lived alone in a basement apartment and worked as a heavy industrial cleaner in a shopping mall.

Family Development

Mrs. Pageau's husband had recently died. His burial had occurred two weeks prior to her hospitalisation. This family faced a major transition. Alain, in agreement with his brothers, proposed that Mrs. Pageau move in to live with him after she was discharged from the hospital. Mrs. Pageau feared that if she moved in, conflict over her grandchild's noisy behaviour was inevitable and she was afraid that such conflict would permanently damage her relationship with her son.

Family Function

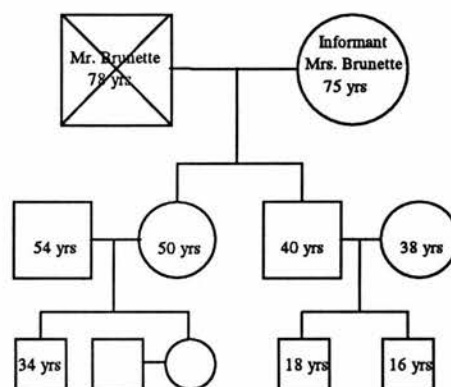
Functionally this family appeared to communicate their thoughts and feelings. The interviews with each son and with Mrs. Pageau suggested that they knew each other well. They used similar words to describe each other and all identified Alain as the caretaker. They all wanted information directly from the doctor. They all felt very protective of their mother, who they characterised as a strong, independent person. It is difficult to say whether or not communication between members was open and clear but the warmth and affection between these men and their mother was powerful. They said that their recent experience with their father's illness would help them to find necessary resources for Mrs. Pageau. Alain has taken on all household tasks such as dish washing, cleaning, and cooking.

Figure 3. The Pageau Family Profile

Illness Trajectory

Mrs. Brunette had a long history of heart disease, experiencing her first heart attack twenty years ago. She had been on medication since that time. Five years ago she underwent back surgery and during the operation she experienced a heart attack and 'almost died' according to her daughter-in-law. She had been 'fine' up until a few weeks ago when her husband of over 50 years suddenly died. As she was being admitted to the hospital her husband was pronounced dead in the emergency department of the same hospital. At that time she was only hospitalised for a few days. However, two weeks later she was readmitted in the middle of the night with an acute episode of chronic heart failure. She was told that she had a 'leaking valve'. According to Rolland's Stages of illness Mrs Brunette is in the chronic or long haul phase.

Family Composition



Note: Mrs. Brunette has 14 children.
Genogram shows only the two who were interviewed.

Family Context

Mrs Brunette was a French Canadian, Roman Catholic who had a primary school education. Prior to the death of her husband she had lived in a small two bedroom, one storey home which they owned.

Family Development

This family was in the process of adjusting to the incorporation of Mrs. Brunette's daughter, son-in-law and mentally handicapped son into her household. Her small house was within walking distance of her oldest daughter's home and the homes of many of her other children. Mrs. Brunette and other family members all agreed that it would be best for Mrs. Brunette if her eldest daughter moved into Mrs. Brunette's home to look after her. Mrs Brunette was grieving the very recent death of her husband.

Family Function

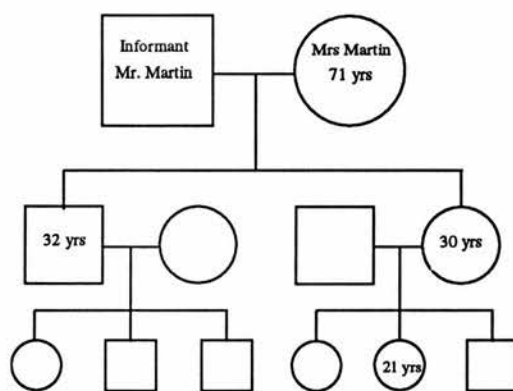
Functionally this family appeared to communicate thoughts and feelings in varying ways to varying degrees. Mrs Brunette and her daughter appeared to be very close. The family was large and many differing opinions were held by family members about the seriousness of Mrs Brunette's heart condition. These differing opinions became a source of conflict between family members. Communication seemed open between some family members while not between others. Mrs. Brunette was very quiet and passive--many of her answers were monosyllabic. Her oldest daughter was doing all internal household chores and had taken on responsibility for Mrs. Brunette's health care, a responsibility previously held by Mr. Brunette.

Figure 4. The Brunette Family Profile

Illness Trajectory

Mr. Martin experienced his first heart attack in 1989. At that time his family were told that it was unlikely that he would survive. They have vivid memories of their experience waiting for news in the emergency department. Since that time Mr. Martin has been repeatedly hospitalised for congestive heart failure. As well, he has been diagnosed with diabetes and during the last year he was told that he had cancer of the prostate gland. During prostate surgery he experienced a cardiac arrest and so the procedure was interrupted and never completed. Since that time the cancer had metastasised and he was being treated medically. He had been in hospital at least five times during the past year. His most recent hospitalisation was to have his cardiac medications adjusted because he was experiencing severe nocturnal dyspnoea and had extensive peripheral oedema. During hospitalisation his diuretic medication was increased from 80 mg three times a day to 80 mg of Lasix four times daily via intravenous. He received continuous oxygen and was placed on bed rest in an attempt to alleviate the lung congestion and peripheral oedema. He was discharged home on oxygen (a new development) after 11 days of hospitalisation. His feet continued to be swollen although they were considerably less so than they had been on admission and they were no longer painful. According to Rolland's illness typology Mr. Martin was in the terminal phase.

Family Composition



Family Context

The family was white, Anglo-Saxon, and Protestant. Both Mr. and Mrs. Martin had completed secondary school. Mr. Martin went to an elite private school. Both children were university educated. The Martins were both retired and lived in a small, two bedroom, semi-detached home that they owned mortgage free.

Family Development

This family was in the process of dealing with Mr. Martin's deteriorating condition and possible death in the foreseeable future. This family was in the retirement stage of family development.

Family Function

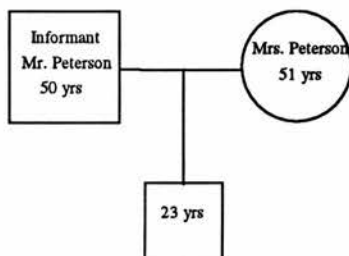
Functionally this family appeared to communicate thoughts and feelings somewhat. Mrs. Martin and her children seemed to be very close. The son said that he and his sister were closer to their mother because she was always there for them while Mr. Martin had often been absent when they were young. Communication seemed open between the son and mother but more guarded between the son and father. The son said his mother did not want to talk about what was happening to Mr. Martin. Mrs. Martin expressed her fear that the end was near for her husband. She had not talked about these fears with him. Mr. Martin was unable to do any household work or outside chores. He looked after his medications independently. His wife had no knowledge of his medications. Mr. Martin's social life revolved around his volunteer work as a fundraiser and member of the executive of a local charitable organisation.

Figure 5. The Martin Family Profile

Illness Trajectory

Mr. Peterson had been hospitalised twice during the same month for heart problems. During his first admission, he was told that he had had a heart attack. Two weeks after being discharged from the hospital he was readmitted with congestive heart failure. Prior to the first hospitalisation Mr. Peterson had been healthy and had never been hospitalised. Mr. Peterson is in the crisis phase of Rolland's stages illness typology.

Family Composition



Family Context

The Peterson's were white, Anglo-Saxon Protestants who attended church on a regular basis. Mr. and Mrs. Peterson were both high school graduates. Mr. Peterson was employed as a maintenance worker, a job he had held for the past twenty years. He faced potential unemployment due to the down sizing and restructuring that was happening at his place of work. Partly in response to concerns about Mr. Peterson's employment, Mrs. Peterson had taken a homemaker course and was working at a government agency. Mr. Peterson lived with his wife and son in a three bedroom, single story, family dwelling that was mortgage free. His 46 year-old brother was dying of heart transplant rejection in another hospital.

Family Development

Within the last year, Mr. and Mrs. Peterson had experienced the loss of an extremely close family friend. Mr. and Mrs. Peterson had been emotional mainstays for their friend's wife who had not only lost her husband but also her 23 year-old son who was killed in a car accident. Watching their friend die and assisting his wife in her grief for both her husband and son had a profound impact on their lives. Developmentally this family was in the launching stage, as their son was at the point of getting married and leaving home. Their son lived at home because although he had graduated from college he had been unable to find a full-time job. The family was moving into the middle-aged stage of the family life cycle with primary tasks of reinvesting in couple identity and developing independent interests.

Family Function

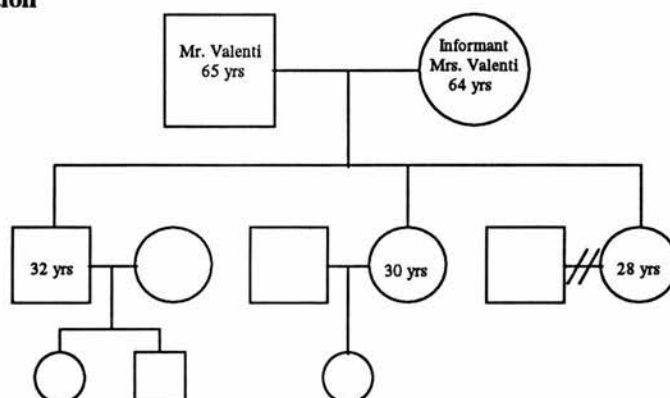
Functionally this family appeared to communicate thoughts and feelings to some extent. The communication between Mrs. and Mr. Peterson was clear and open, as was the communication between Mrs. Peterson and their son. The relationship between mother and son seemed close and verbal. However, the relationship between father and son was characterised by both as 'not close'. Father and son both said that they have become closer since Mr. Peterson's illness although they said they don't talk to each other about emotional things. Mr. and Mrs. Peterson were interdependent. Mr. Peterson was feeling very vulnerable because of his work situation. Mrs. Peterson was very protective of her husband. She was very worried about him, and very acutely attuned to his illness-- pills, visits to the doctor, diet, and emotional responses. She watched and monitored everything. The atmosphere was a little tense. The son was protective of his father and mother. He was doing chores without being asked and expressed worry that his father would mow the lawn or dig the garden if he did not get to it first. Household chores were shared. Mr. and Mrs. Peterson both cooked, worked in the garden, and made purchases together.

Figure 6. The Peterson Family Profile

Illness Trajectory

Mrs. Valenti had a long history of heart disease having experienced her first heart attack in 1980 when she was 48 years old. Subsequently, in 1985 she had coronary artery bypass graft surgery. She almost died during the surgery. She spent a month in the intensive care unit, followed by weeks in hospital. She was so incapacitated by her illness that she was house-bound and bedridden for the entire year after her cardiac surgery. She experienced overwhelming fatigue, severe nausea and could not eat anything but 'popcorn'. She and her husband attributed her current stabilised health status to the ongoing efforts of her cardiologist to find an effective combination of medication. She had recently discovered the cardiac rehabilitation programme and had badgered her cardiologist until he allowed her to attend the program. She reported experiencing angina and shortness of breath on exertion and had persistent peripheral oedema. She had difficulty sleeping which she attributed to her fear of not waking up ever again. The degree of damage to her heart should put Mrs. Valenti in the terminal phase. However, by sheer will combined with careful regulation of her medications and activity level she was in the chronic or long haul phase of her illness.

Family Composition



Family Context

Mrs. Valenti and her husband lived in a suburban, small, three-bedroom, mortgage-free, bungalow. They have lived in this home for most of their married life. The house and yard are immaculately kept. An extremely expensive North American luxury car sat in the driveway. Mr. Valenti emigrated from Italy in the 1950's while Mrs. Valenti came to Canada from Ireland with a girl-friend when she was 18 years old. Mrs. Valenti had no formal education and taught herself to read and write. Her mother died of heart disease at the age of fifty. Although retired, Mr. Valenti works occasionally on a consultant basis for the company he once owned in partnership with others.

Family Development

This family is in the process of maintaining Mrs. Valenti's heart in a stable condition. The family is in the retirement phase of family development.

Family Function

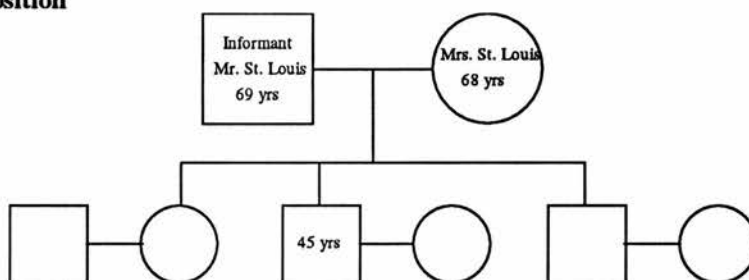
Functionally this family communicated thoughts and feelings fairly openly although there were some things that Mr. Valenti did not discuss with his wife. He was very, very protective of her. He was the primary care taker. The youngest daughter was very close to her parents, in particular to her mother. The daughter had a severe hearing disability that made her very special in her mother's eyes. Mr. and Mrs. Valenti are totally interdependent. The Valentis said that they were also close to their older children. Mr. Valenti handled all the finances and looked after Mrs. Valenti's medical regimen. Initially, following surgery, she simply did not have the physical energy to do any household chores. She did some light household chores such as cleaning, tidying and cooking but he had hired a housekeeper to do the heavy work. Mrs. Valenti was a homemaker and mother throughout her married life. She had never worked outside the home since they were married.

Figure 7. The Valenti Family Profile

Illness Trajectory

Mr. St. Louis had a long history of heart disease. He first started having cardiac problems in the 1970's that were related to excessive consumption of alcohol. When I met him he had been hospitalised for severe congestive heart failure complicated by pneumonia, liver, and kidney failure. At the time that I saw him he had just been transferred from the intensive care unit to the floor. He was bedridden, both legs were extremely oedematous and he was breathing with the aid of an oxygen mask. He could not speak more than a few words without gasping for breath. He was catheterised and had an intravenous running into his left arm. He desperately wanted to have heart surgery. He had mitral valve surgery in 1991 and the valve was now leaking, however, his physical condition was so precarious that he was not a candidate for surgery. His wife, grand daughter and son were in the room visiting with him when I arrived. Mr. St. Louis had been hospitalised on three different occasions in the past four months. According to Rolland's typology, Mr. St. Louis was in the terminal stage of his illness.

Family Composition



Family Context

The St. Louis's were French Canadian, Roman Catholics. Mr. St. Louis had a grade 5 education while Mrs. St. Louis had completed grade 9. Up until retirement they jointly managed a business that they owned together. Their daughter lived in the vicinity, was married and had children. Both sons lived several hundred miles away. The 45 year-old son that I spoke with was self employed, married to a nurse and had children. The second son was also married with children.

Family Development

This family is in the process of adjusting to the terminal nature of Mr. St. Louis's illness. The family is in the retirement phase of family development.

Family Function

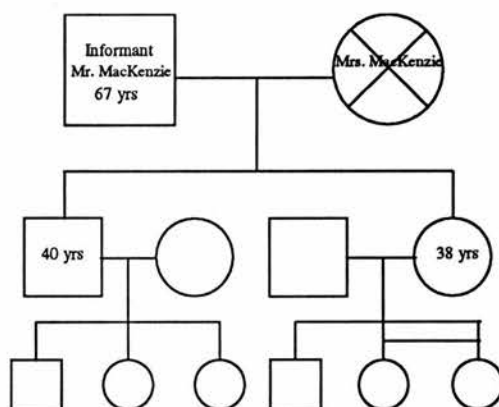
Functionally this family communicated thoughts and feelings quite openly. The children were close to their parents, particularly to Mrs. St. Louis, whom the son characterised as a strong person. Mr. and Mrs. St. Louis had been married for 50 years and Mr. St. Louis was totally dependent on his wife and afraid to be left alone. Mr. St. Louis talked openly about not wanting to live. The son also spoke openly of his father's imminent death. Mrs. St. Louis broke down crying while talking about her husband's preference for death rather than life. Mr and Mrs. St. Louis indicated that Mrs. St. Louis was the primary caregiver. Mrs. St. Louis's mother, who is in her late 80's, had fallen and broken her hip and subsequently moved into the St. Louis household so that she could be cared for by Mrs. St. Louis. Consequently, for several months Mrs. St. Louis looked after her husband, as well as her mother. Mrs. St. Louis was totally responsible for all household chores and all tasks related to living together as a family.

Figure 8. The St. Louis Family Profile

Illness Trajectory

Mr. MacKenzie had been a diabetic for the last 10 years and had been treated for congestive heart failure for several years now. He had his leg amputated last year because of the diabetes. He had increased difficulty breathing and his cardiac pain worsened after he had his leg amputated. Some of the doctors wanted to do coronary artery bypass surgery. However, his cardiologist felt his kidneys and liver would not withstand an operation. I first met Mr. MacKenzie when he was admitted to the intensive care unit on an elective basis. He was in hospital to have intravenous medication for his failure and to have his heart failure medications adjusted. His main concern was not when he would die but how he would die. Mr. MacKenzie could not talk about his own health without referring to his wife's death. According to Rolland's chronic illness typology, Mr. MacKenzie was in the terminal phase of his illness.

Family Composition



Family Context

Mr. MacKenzie was a white, Protestant who had been an active church member until very recently. He was retired and had recently sold his home and moved into a retirement/nursing home. His son worked for a large, local company while his daughter lived several hundred miles away and had a job as a health care professional. Both Mr. MacKenzie and his son identified his daughter as his main caregiver.

Family Development

This family is in the process of adjusting to the terminal nature of Mr. MacKenzie's illness. Mr. MacKenzie believes he has 6 months to a year to live. Mr. MacKenzie was still grieving the death of his wife. This family is final stage of family development adjusting to the death of a spouse.

Family Function

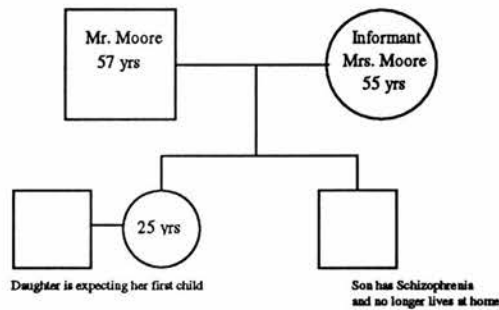
Functionally this family appears to communicate thoughts and feelings fairly openly. Mr. MacKenzie said he felt closer to his daughter than to his son. The son spoke at great length about his father, his illness and the care he had received. The son could not talk about his father's illness without recounting events surrounding his mother's illness and death. He, his sister, and his father cared for Mrs MacKenzie for seventeen months at home. He described, in detail, the kind of complex care that he and his sister gave their mother. Mr. MacKenzie said that he and his daughter had had frequent heated discussions about the need for him to move because of increasing difficulties living alone and maintaining his home and garden. He wanted to move into an apartment. She wanted him to move into a protected environment where he could be monitored and receive care as needed. This discussion went on for several months and finally ended with Mr. MacKenzie moving into a retirement home.

Figure 9. The MacKenzie Family Profile

Illness Trajectory

Mrs. Moore experienced her first heart problems as a young 18 year old when she was diagnosed with valve problems due to rheumatic heart disease as a child. She had open-heart surgery and repair and replacement of heart valves in 1985. The procedure was unsuccessful and was repeated three months later. At around the same time her son was diagnosed with Schizophrenia. More recently, she was in a car accident that precipitated an infarction of a part of her spinal cord. She was left with severe bowel and bladder problems and weakness in her legs. Gradually she regained control over her bowels, bladder and legs. When I met her, she could walk with the aid of canes however she relied heavily on a wheeled walker. She detested being dependent on the walker or being dependent on people. The spinal cord injury had forced her to retire. She replaced this loss with volunteer work. For the past two years she had experienced worsening of her heart failure. She was reluctant to undergo heart valve surgery. However, continual deterioration of her health culminated in admission to hospital in May 1996. At that time she was treated for heart failure and for bleeding caused by her anticoagulants therapy. She then had valve replacement surgery. Her condition following surgery was extremely serious with numerous near death episodes. Finally, one week after the surgery while she was still in ICU, a tracheotomy was performed and she was booked for emergency repeated valve replacement. Her condition following surgery was precarious for days. She remained in ICU for over a month. On being transferred to the floor, she was lethargic, depressed and continuously nauseated, possibly due to the multiple medications she was taking. The nausea and lack of appetite slowly improved, she gradually regained strength, and was transferred to the rehabilitation unit of another hospital. In total, she spent six months in hospital before she was finally discharged home. Mrs. Moore was in the chronic (long haul) phase of chronic illness.

Family Composition



Family Context

They were White, Anglo-Saxon, Protestants who did not attend church. Mr. Moore was an office worker as was their daughter. Their son was unemployed and they did not know where he lived.

Family Development

This family was in the stage where all children have been launched, although the son continued to be a source of problems and concern. The family was in the process of adapting to Mrs. Moore's health deterioration.

Family Function

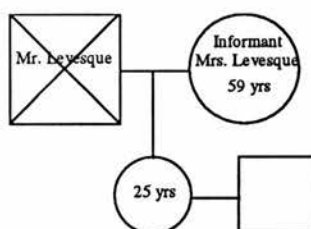
Functionally this family appeared to communicate thoughts and feelings. They have been through so much together and seemed to know each other very well. Mr. Moore was very protective of his wife. Mrs. Moore and her daughter appeared to be very close, as did Mr. and Mrs. Moore. The daughter said that her husband was also deeply concerned about Mrs. Moore. The daughter said she relied heavily on her husband and his family. She felt she had to be strong for her father and could not burden him with her feelings and fears when her mother was so ill. Mr. Moore had been doing all the internal household chores. Physically, Mrs. Moore was not able to do the cleaning, cooking or shopping. She was gradually taking back some household chores. Mr. Moore liked cooking so that was not a problem. Mrs. Moore was attending the cardiac rehabilitation program, which she found quite useful.

Figure 10. The Moore Family Profile

Illness Trajectory

Mrs. Levesque was 52 years old when she had her first heart attack in 1989. Her only daughter was fifteen or sixteen years old at the time and Mrs. Levesque was a widow. Mr. Levesque had died of cancer in 1982. Mrs. Levesque looked after him at home. When I met Mrs. Levesque she was attending the cardiac rehabilitation programme and as she said, "nobody ever told me anything about my heart until the nurses there did." She did not know that she had congestive heart failure and did she know what heart failure meant. She had experienced shortness of breath, abdominal ascites, and peripheral oedema that gradually got worse during the past year. In December she had such difficulty breathing that her neighbour took her to the doctor's office. On seeing her, the doctor immediately suggested she go in hospital. She did not realise her symptoms were related to her heart. She thought she had an ulcer, or that she was experiencing menopausal symptoms. She was admitted in hospital with a diagnosis of congestive heart failure and was hospitalised for a week including several days in intensive care. During hospitalisation she was seen by a cardiologist and given diuretics and other cardiac medication that saw her lose over 30 pounds. Mrs. Levesque was in the terminal phase of her chronic illness.

Family Composition



Family Context

Mrs. Levesque was a non practising, Roman Catholic, French Canadian. She had a primary education (eight years). She was a homemaker and lived alone in a thirty year old house that she owned. She had lived on social assistance since her husband died of cancer in 1982. She never remarried although she had a boyfriend. Her mother died of heart disease at the age of 50. Mrs. Levesque had 17 brothers and sisters. Several brothers died of heart disease in their 40's and three of her sisters were living with heart disease. Her neighbours looked after her house and dog for her while she was in hospital.

Family Development

This family was in the process of adjusting to Mrs. Levesque moving in with her daughter and partner. Since Mrs. Levesque's hospitalisation in December the daughter, her partner, and Mrs. Levesque have decided together that Mrs. Levesque would sell her home and move into the basement apartment. They were adjusting to the terminal nature of Mrs. Levesque's illness.

Family Function

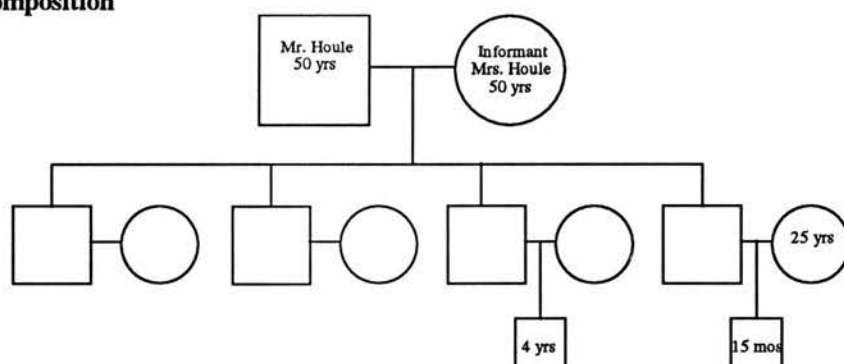
Communication between mother and daughter was open, warm and affectionate. They said they could talk to each other about anything. Mrs. Levesque said that her daughter and partner had told her that the apartment was always meant for either his mother or her. Her illness meant that she needed to be with them and that was fine. Mrs. Levesque spoke of her daughter's partner with warmth. Mrs. Levesque also had a good relationship with her sister. They talked often on the phone and she came to visit when Mrs. Levesque was hospitalised. Mrs. Levesque has had a lot of help from her daughter and her partner. She looked after her own medication and treatment. Her daughter wanted to know everything she could about her heart condition and medication. Mrs. Levesque could no longer vacuum, clean the bathroom, or do any housework. She was able to cook and was looking forward to cooking for the three of them after the move. Her daughter was cleaning both homes and her partner was clearing the driveway and stairs of snow. They were anticipating that moving in with the daughter would reduce the daughter's fears and workload.

Figure 11. The Levesque Family Profile

Illness Trajectory

In the fall Mrs Houle was admitted in hospital with a diagnosis of possible heart attack. Her diagnosis remained unclear for the first few days that she was in the intensive care unit. Since that hospitalisation she had spent time in two hospitals and was eventually diagnosed as having had a heart attack. She had coronary angiograms done which demonstrated severe blockage of both main arteries. She had symptoms of heart failure and was being treated medically. She had been told that her situation would be reassessed in the spring by the cardiac team at the hospital. She did not want to wait until then to have surgery. She thought it would be more appropriate to attend the cardiac rehabilitation unit after she had had surgery. She felt that many of the other patients that she had met at the cardiac rehabilitation program had been to cardiac rehabilitation, then they had experienced a heart attack and then they had had surgery. She wanted to avoid this scenario and have surgery right away. She was a heavy smoker and was trying to quit. Since being discharged from the hospital she had experienced frequent episodes of chest pain. Several days prior to my visit she had taken three sprays of nitro-glycerine and the pain finally subsided. However, her husband phoned the doctor and cardiac rehabilitation because he was so concerned about her. She had not told him or anyone else about previous episodes of pain. Mrs. Houle was in the crisis phase of her chronic illness.

Family Composition



Family Context

The Houle's were French Canadian and they were devout Catholics. Mr. Houle worked with elderly members of the church and sang in the choir. Mrs. Houle read her bible every morning on rising. They both had secondary education (12 years). She had always been a homemaker and was the primary caretaker of her 15 month-old grandson. For the last nine years Mr. Houle had been on disability pension due to stress syndrome. They live in low rental subsidised housing.

Family Development

This family was the retirement phase and was adjusting to Mrs. Houle's illness. Mr. Houle had been sick with stress syndrome, a condition that some family members did not consider to be legitimate, whereas the seriousness of Mrs. Houle's illness seemed to frighten everyone.

Family Function

Communication seemed fairly open. Mr. Houle clearly expressed his feelings and opinions about his own illness, about his wife's illness, and about his sons. He did not want any of his sons present at a family interview. Mr. Houle resented their intrusion and felt he was the person responsible to take care of Mrs. Houle. During the joint interview, Mrs. Houle spoke only when I deliberately shifted the focus to her. Mr. Houle suggested that he and Mrs. Houle were very close, Mrs. Houle acquiesced. He felt he was the emotive person in the family who talked about his feelings while she seldom, if ever, did. Mrs. Houle said she was close to her mother, sisters, and sons. Since being hospitalised Mrs. Houle has very limited abilities to do any work at all. She was particularly upset about not being able to care for her grandson. Mr. Houle was doing the shopping and cooking. He emphasised how difficult it was to buy the food Mrs. Houle needs, citing the cost as prohibitive when living on a very limited income. He was trying to get a disability pension for Mrs. Houle.

Figure 12. The Houle Family Profile

CHAPTER 6

UNCERTAINTY

Uncertainty emerged from the data as a major conceptual category through the analytic process of constant comparative analysis. The analytic process used has been described in detail in Chapter 4.

Constant comparison and questioning the data were analytic processes that were used to move substantive codes to the theoretical level. Constant comparison was used to compare data with data and category with category. Comparing data with data involved: 1) comparing different patients' and family members' accounts of how patients came to hospital, their understanding of patients' symptoms, and how they and their families handled issues around coming to hospital, being discharged and talk of when and how dying would happen; 2) comparing data from the patients and their family members at different times.

A conceptual category can be developed from substantive categories by determining whether the substantive categories are properties, conditions or consequences and by identifying how a conceptual category changes and relates to other categories. Identifying substantive codes as either properties, conditions or consequences helped to develop the conceptual category uncertainty while at the same time ensured that uncertainty was grounded in the data. The following questions were used to examine the data to decide whether substantive codes could be identified as properties, conditions or consequences of uncertainty:

- 1) What were ill patients and their families uncertain about?
- 2) At what time did uncertainty occur?

- 3) What were the consequences of it?
- 4) How was it handled?
- 5) What behaviours or activities precipitated uncertainty?

The data were also examined to determine whether uncertainty varied according to the phase of illness and knowledge of diagnosis. In the following sections of this chapter data will be presented to show how the concept of uncertainty was developed as a major category through the identification of some of its properties, delineation of some of the conditions under which it occurred and portrayal of its consequences for patients and their families.

Analysis of the data revealed that patients and family members were uncertain about whether or not to go to the hospital when symptoms occurred, about what to do after discharge from the hospital, and about what to expect in the future.

Uncertainty About Going to the Hospital

In this section, excerpts taken from patients' and family members' accounts of how patients came to be hospitalised will be used to illustrate subcategories that were linked to uncertainty about whether or not to go to the hospital. Topics that were explored in relation to this uncertainty included not knowing, not understanding or not being sure about what symptoms meant, trying home remedies and medications, dislike of hospitals, phase of illness, knowledge of the patient's diagnosis, and whether the admission was on an elective or emergency basis.

Not Knowing What Symptoms Meant

Symptoms such as difficulty breathing were not understood, not recognised or were confused with other less threatening conditions such as an upset stomach, the

“croup” or a “nasty cold”. Several patients exhibited confusion about the cause of their symptoms and uncertainty about whether or not to go to the hospital. The accounts of relevant events that preceded the hospitalisation of Mrs. Roy, Mrs. Pageau, and Mrs. Levesque illustrated the dilemma of not knowing what was the matter and not recognising what was causing the symptom.

In her account, Mrs. Roy, a 77 year old woman with a 16 year history of heart disease, described the events that took place prior to being hospitalised for congestive heart failure. During the interview, it quickly emerged that she had already been hospitalised for heart failure three times during the previous four months. On the first occasion she experienced heart failure because of uncontrolled atrial fibrillation and required cardioversion on arrival in the emergency department. On the second and third occasions she arrived at the hospital in severe heart failure but did not have atrial fibrillation. On each occasion, her daughter or other relative had initiated the call for the ambulance.

ER So how did it (*getting acutely sick*) start this time? Before you came to the hospital on Saturday, what happened?

Mrs. Roy I went to bed and I drink coffee. I went to bed..... I wasn't feeling good, I said, I shouldn't drink that coffee. I drink too much! I got up. I went to the bathroom and I started, how you say that, "rotter"? (*French Canadian colloquial term*)

ER Burping?

Mrs. Roy Yes, burping and then I had to go to the bathroom. I went to the bathroom, I go to bed and I start burping, burping. OH, MY GOD, what's the matter with me?

Mrs. Roy expressed confusion about just exactly what was happening to her. She was uncertain about the cause of her symptoms and at first, she attributed “not feeling good” to having drunk too much coffee. She then recounted burping and having to go to the bathroom, going back to bed, and burping again. In a subsequent interview with Mrs. Roy’s daughter (Mrs. Roy-D) when I asked if Mrs. Roy had

experienced any other symptoms besides the difficulty breathing she also referred to “burping”.

Mrs. Roy-D She says, after she eats and after, she gets... like burping.
ER Burping. She told me about that burping.

Mrs. Roy-D And um, she thinks that it's her food, a lot of times. But the nurse was telling us that it's angina. Like, she feels like she's got a ball in her stomach, you know. And the nurse was saying, I don't think it's your food. It's your heart, you're having an attack, you know...an angina attack.

Mrs. Roy's daughter said that her mother thought that the burping she experienced was related to stomach problems rather than heart problems. The symptom Mrs. Roy had experienced was ambiguous in that burping could easily be interpreted as being caused by a stomach upset rather than by her heart disease. Similar ambiguity arose about the meaning of the symptom of difficulty breathing. In this instance, Mrs. Roy's daughter likened her mother's breathing difficulty to the croup.

Ambiguity about the cause of symptoms was experienced by other patients who also reported not recognising or understanding the cause of their symptoms. Mrs. Pageau, was a 61 year old woman who had an eight year history of heart problems including atrial fibrillation, mitral valve disease, and angina. She was admitted to the hospital in acute severe congestive heart failure. Mrs. Pageau recounted thinking that her difficulty breathing was “like somebody has a nasty cold”. Later in the same conversation, she likened her coughing to “like somebody had the whooping cough”. She stated she would never have gone to the hospital on her own because what she was experiencing did not feel like heart pain. Symptoms of difficulty breathing and coughing were ambiguous and she did not attribute them to her existing heart condition. She said that her son picked her up, carried her out to the car and drove her to the hospital. Furthermore, she said that if she had been

alone she would never have gone to the hospital. She didn't know what was happening. She didn't make a connection between symptoms that she perceived as a "very nasty cold" and her pre-existing heart disease.

- Mrs. Pageau Well, uh lately I hadn't been feeling too good. And we were burying my husband so he (*Mrs. Pageau's son*) figured he'd spend a week with me. So, I wouldn't be alone. And really, I'm glad he did because I couldn't have never come to hospital. Cause it didn't feel like heart pain.
- ER No? What did it feel like?
- Mrs. Pageau Like somebody has a nasty cold. A very, very nasty cold. Coughing. I wasn't bringing up phlegm or anything. And then when I got here they said I had so much water in my lungs it was TERRIBLE. So you know, you can't say how come it got so. Just from coughing so bad.

Later during the interview, Mrs. Pageau, a diabetic, went on to tell me how she thought that her symptoms were related to her diabetes also being out of control as shown in the following excerpt.

- Mrs. Pageau But I just was tired and like as if I was in an oven all the time, you know.
- ER Yeah.
- Mrs. Pageau Hot, ready to pass out and I thought, oh well, my diabetics (*diabetes*) gone crazy, you know. But my diabetics never went crazy.

Mrs. Pageau referred to another ambiguous symptom, being tired, that was also frequently reported by other patients or their families. Being more tired than usual could be attributed to many things. As Mrs. Roy's granddaughter (Mrs. Roy-GD) noted her grandmother looked tired, tired and worn out.

- ER The heart disease, especially failure, when the pump isn't working as well, has an impact on your ability to physically do things. Have you noticed that?
- Mrs. Roy-GD Well, I know she looks tired..... She's not herself.
- ER And that's changed in the last few months?
- Mrs. Roy-GD Yeah.
- ER So that....
- Mrs. Roy-GD She looks just tired, worn out.

Her granddaughter also said that she thought her grandmother didn't understand the connection between her heart problem and being tired and needing to balance rest and activity. Tiredness rose spontaneously as a topic during the family interview and Mrs. Roy's daughter emphasised with her mother the need to avoid

getting tired by resting. This was one of the areas that the nurse in the hospital had stressed as being important to recognise.

Mrs. Roy-D. Mom, she (*the nurse*) said you have to rest before you get tired. Mom you have to!
(*Mrs. Roy interrupts*)
Mrs. Roy Yeah.
Mrs. Roy-D. When you're tired, it's TOO LATE!

During the hospital interview with the nurse (Mrs. Roy-N) the following comments were made concerning Mrs. Roy's understanding of her symptoms.

ER When you talked with Mrs. Roy did, how specific did you get? You know, in terms of understanding what her symptoms mean.
Mrs. Roy-N. Uh, I was very specific about the early onset of the kinds of symptoms she should recognise. Hum, not being able to lie down flat, having to have extra pillows and hum, finding she's more tired than usual. All the kinds of things that they might not think are markers but are.

As illustrated in the following excerpt, yet another patient, Mrs. Levesque, painted a picture of confusion and uncertainty as she tried to figure out what was causing her symptoms of shortness of breath, pain, and sweating. Mrs. Levesque, a 59 year old woman, had experienced a heart attack in 1989. When I met her, she was a new patient in the cardiac rehabilitation programme and had been hospitalised for congestive heart failure four weeks prior to being interviewed. She described the events that led up to her emergency admission to the hospital telling me that she had become progressively more ill over the past year and as a consequence had been to see her family doctor several times. Her symptoms were ambiguous and gradually got worse over time, culminating in a crisis situation at the doctor's office.

ER And this time, what happened? What brought you to the hospital in December?
Mrs. Levesque They say it was a congested heart failure.
ER Uh, huh.
Mrs. Levesque And uh (*short of breath*) I used to be small you know, more on 100 (*pounds*) and uh, last summer I kept gaining and gaining and I had a big belly, you know and I guess it was all water. Cause, I went to my doctor and I would sweat--OOOH! badly!! And every time I go to my family doctor, he give me pills for the sweating. He give me pills for that and then finally when that happened, he said, he should have listened to me. ALL THOSE SIGNS I HAD!
ER Uh huh.

Mrs. Levesque And then, when I went in the hospital in December, I was really sick. Coughing, OOOH!!!

ER Tell me what happened then. Did it happen at night? What happened?

Mrs. Levesque The first heart attack?

ER The one that you had in December?

Mrs. Levesque Oh, in December. Well, it was building up from day to day and finally my neighbour took me to the doctor. And uh, I could hardly breathe when I came up those stairs. So, I hide myself in the washroom and I use my pump. AND THEN, OH, GOD, I COULD HARDLY SIT. So, right away he asked me who drove me there, cause he knew I couldn't walk there (*to the medical clinic*).

ER Yeah.

Mrs. Levesque So, I said, my neighbour. So, he said, would he take you to the hospital? Well, I said, I'm sure he won't mind, you know.

ER Uh, huh.

Mrs. Levesque So, right away, he phoned and they kept me. I was wearing diapers with all the water.

ER Yeah.

Mrs. Levesque AND SWEATING, OOOOH! Everybody would say, you know, it's not that hot!

ER Yeah.

Mrs. Levesque But to me, I would take four or five showers and still it..and I thought well, maybe the menopause. You think all. And I've got an ulcer. So, you think it's all that, you know. That it's not really the heart.

ER Yeah, yeah. You didn't...did you have any pain at all?

Mrs. Levesque No. Not too much, no.

ER No?

Mrs. Levesque When I cough, it will hurt.

ER Yeah, yeah, but other than that?

Mrs. Levesque No, no (*shakes her head*). And I was always out of breath. Oh, yes,

ER Short of breath?

Mrs. Levesque I couldn't, yes, short of breath.

In her account, Mrs. Levesque said that she thought her symptoms could have been related to the menopause or her ulcer, anything but heart disease. Weight gain and profuse sweating are symptoms that could easily be confused as being caused by menopause in a woman of her age. The weight gain she reported experiencing was entirely in her abdomen. Abdominal weight gain can be a symptom of right-sided heart failure and could easily have been misinterpreted as being related to the weight gain sometimes associated with the menopause and/or aging.

Self-treatment of symptoms. Several patients tried to alleviate their symptoms themselves by using a variety of self-administered antidotes. The behaviours that Mrs. Roy undertook in response to her symptoms suggested that she was not sure what was causing her to feel so ill. In her search for relief, Mrs. Roy

tried several different home remedies including using a damp cloth, going to the toilet, and taking some nitroglycerine.

Mrs. Roy So, my daughter hear me coughing and she come down, "Are you sick?" I don't know, but I don't feel good. "Well", she said, "if you feel, don't feel good, you better not wait because we're far from the hospital here." So, I, I took two, two of those Nitros and I put some cold cloth and that helped a little bit.

These activities helped only a "little bit". Other patients also tried taking home remedies to relieve their symptoms. Mrs. Brunette, a 75 year old woman, had a long history of heart disease and had been managing her illness at home until the sudden death of her husband. She had been admitted twice for heart failure in the two weeks following the death of her husband. I interviewed her during her second admission. As shown in the following excerpt, Mrs. Brunette and her family tried to alleviate her difficulty breathing by getting her to breathe into a paper bag. In a subsequent conversation that was not taped, I discovered that one of her daughters-in-law was a nurse. This daughter-in-law thought Mrs. Brunette's difficulty breathing was due to hyperventilation brought on by anxiety over the recent death of her husband. Mrs. Brunette's difficulty breathing occurred on the evening of her husband's funeral following a traumatic family interaction between herself and other family members at the funeral parlour. Family members had attributed her breathing difficulties to anxiety, rather than to her heart disorder. However, her difficulty breathing was due to heart failure and she was admitted to hospital. Mrs. Brunette and her daughter (Mrs. Brunette-D) recounted the events of that night:

ER	Can you tell me what, what happened?
Mrs. Brunette	I couldn't breathe, I don't know. I woke up. I don't know if I was dreaming that night or what. But, I couldn't breathe.
Mrs. Brunette-D	I don't know what got me out of bed. I just flew here.
ER	Um hum.
Mrs. Brunette	No fun, when you can't breathe. I couldn't catch my breath. My daughter-in-law came over.
Mrs. Brunette-D	If she gets that again, I told her, we get the ambulance.

Mrs. Brunette She got a bag there to blow in.
 ER But it didn't help?
 Mrs. Brunette Nope.

In a similar situation, Mrs. Pageau, in describing what happened the night that her son took her to the emergency department, related how she opened the windows and doors in a desperate, unsuccessful attempt to ease her breathing.

Mrs. Pageau Just coughing. I was coughing like somebody had the whooping cough.
 ER Oh, and did you feel like you had fluid in your lungs?
 Mrs. Pageau Yeah.
 ER Were you coughing anything up?
 Mrs. Pageau Nothing up. Just cough and cough and cough and cough. Until my son came in the bedroom. He had stayed with me that night. And he says uh, Mom, I'm gonna take you to emergency. I said, oh son, don't bother me. Go to bed. Leave me alone. And then, I couldn't breathe. So, I opened the window. I opened my bedroom window. I opened my bedroom door because my bedroom door opens outside. I still couldn't breathe. So when he came in and he saw that, he just grabbed me in his arms, threw me in the car and brought me here. And that was the last I remembered until uh, Friday.

Dislike of Hospitals

During her hospitalisations, Mrs. Roy had experienced bruising and swelling in both arms from the intravenous and from the taking of blood for tests. When I interviewed her in the hospital she was very emotional and made a point of showing me the extent of the swelling and bruising on both of her arms and hands.

ER Well, and maybe that will help so that you don't come back in a while.
 Mrs. Roy I hope not, my God, look at my hands, poor hands (*puffy, swollen, bruised and painful from repeated intravenous infusions*).
 ER IV (*intravenous*). So, so?
 Mrs. Roy IV's and blood tests.
 ER Yes.
 Mrs. Roy And here to there (*shows me her bruised arms*). I don't like that at all! I don't like that!

Subsequently, when I interviewed her at her home she strongly expressed her desire not to have to go to the hospital again. When she said in the quote below, 'I would sleep under the bed' that was her way of saying that she was willing to do anything to avoid returning to the hospital. This lady had been hospitalised three

times in four months, the latter two episodes being two weeks apart. Each hospital admission occurred at night and on an emergency basis.

Mrs. Roy	I said to my daughter if I knew, if I know I'm going to be OK, I'd sleep under the bed. I don't want to go to the hospital no more.
ER	Yeah.
Mrs. Roy	Oh shoot. It's not funny. Twice in the same month.

Phase of Illness

The patients in each of the accounts related above had histories of heart disease that ranged from six to 30 years. However, they all experienced a sudden, unexpected deterioration in their condition. They all reported severe difficulty breathing heralding a sudden acute exacerbation of their previously chronic but stable cardiac illness. Mrs. Roy's family was told she could die at any time; Mrs. Pageau's family was told if she had another heart attack she would be unlikely to live; Mrs. Brunette was told her condition was very serious; and Mrs. Levesque said that she knew that she could die at any time. Each of these individuals experienced an acute, life-threatening episode of a chronic condition. They were all also being treated with from 8 to 12 different medications, all of which had potentially lethal side effects.

Atypical Cases

Two patients (Mr. Martin and Mr. MacKenzie) were admitted to the hospital on a non-emergency basis for adjustment of their medications. Neither of these individuals exhibited uncertainty about whether or not to go to the hospital.

When I asked Mr. Martin what brought him to the hospital, he explained to me that he had been to see his cardiologist for a regular check up and his medication had been adjusted because he had been experiencing increased difficulty with

breathing. The medication had not helped and he was still having problems breathing and in addition his feet were badly swollen so the doctor told him to go to the hospital.

ER So what were your symptoms when you came in this time last night, what brought you to the hospital?

Mr. Martin Well, I was down to the doctor's office just for a checkup. I had been having trouble breathing and he knew it, so he had changed my dosages of medication and said come back and see me in two weeks. Oh, and then I had to go and get uh, some blood work done and a chest x-ray etc. etc. And it was when I was in there after the two weeks, which was like yesterday morning or yesterday at noon, at two o'clock. Uh, I was REALLY having trouble breathing and these things, ankles and feet were, they were just swollen up like balloons. And uh, you're going back into the hospital, he said. We're gonna get to the bottom of this. So, here I am (laughter).

The following excerpt confirmed his frequent trips to hospital and his familiarity with the environment where he likened the emergency department to "old home".

Mr. Martin Well, we were saying that, I don't know whether it's because I've been into emerg so many times, that uh.... it's like old home.

ER Um hum um hum.

Mr. Martin Uh, I know everybody by their first name and (laughs) They just take a look and they say well, how come you're back here again?

During the family interview confusion between this admission and many previous ones became evident. Mrs. Martin said "this usually happens when he says come and meet me in the hospital" further confirming the frequency of his trips to the hospital. The following excerpt taken from the Martin family interview illustrates their joint recall of his most recent hospitalisation.

Mrs. Martin And anyway, or you called him and told him what was going on. That was it. You called him.

Mr. Martin Yeah.

Mrs. Martin First of all just to have a look over it. And I said, well, I know darn well if you're gonna meet the doctor in the hospital you're gonna need stuff to go in the hospital. You'll be staying.

ER Um hum.

Mrs. Martin *(laughs)* This is usually what happens when he says come and meet me in the hospital and I'll do some tests. Well, you know, he always takes him in for a few days. And it usually ends up for a week.

Mr. MacKenzie was the other patient admitted to the hospital on an elective basis. He had a three year history of heart failure and had also spent a great deal of time in the hospital during the past year. His leg had been amputated a year earlier and he had also experienced several episodes of heart failure. In the following quote he told me about his scheduled appointment with his specialist and described his symptoms of difficulty sleeping and breathing. He went on to describe how the doctor suggested that he be admitted to hospital to have his medications adjusted. He recited the events in a calm, matter of fact manner and did not express any hesitation or ambivalence about making the trip to the hospital. He was admitted to the intensive care unit on an elective basis and that is where I first met and interviewed him.

ER What happened this time before you came into the hospital? How did you come to the hospital?

Mr. MacKenzie Well, I'd been telling the doctor. I had an appointment with the doctor. He seen I looked kinda rough. I couldn't, I haven't been able to sleep properly at night.

ER You couldn't breathe?

Mr. MacKenzie I couldn't breathe.

ER Have you got oxygen at home?

Mr. MacKenzie No, no. Just, ah, I don't know if it would help. I guess it would help, yeah. I have a puffer and that really helps. That helps. I put that on. I use that sometimes.

ER Um um. Anyway, I interrupted you. You were having trouble sleeping so he thought you looked pretty rough.

Mr. MacKenzie Pretty rugged, yeah. But he introduced me to these patches these uh, that really helps.

ER That helps the breathing too?

Mr. MacKenzie That helps the breathing, that helps the breathing, yeah. Yeah, seems to do that.

ER When did you see him this week? You saw him at home?

Mr. MacKenzie I just seen him Friday. He says, how'd you like to come in for 48 hours to try some. Oh no, I seen him Thursday. He says, how'd you like to come in for 48 hours to try some new drugs on you. I says, sure. And that's it.

Mr. MacKenzie had a great deal of trust in his specialist and told me later in our conversation how calm and relaxed he made him feel. During the interview with

him his cardiologist stopped in to chat with him. After he left Mr. MacKenzie spontaneously offered the following comments about his relationship with this physician and how that made him feel.

- Mr. MacKenzie Oh, I could talk to him like I could talk to my kids, yeah, which is not very many doctors you can do that to, you know. Attitude! I don't know what he does to put me in such a relaxed uh, mood or attitude. I was hoping he would stay a little longer.
- ER Maybe it's respect. He respects you as a person?
- Mr. MacKenzie Yeah, yeah. He seems to look at you and he does respect you. Yeah, if you have pain or you're uncomfortable, he's more or less says, I understand. Some way or other. It comes across.
- ER Um hum, um hum it comes across?
- Mr. MacKenzie Yeah, it comes across, yeah, yeah. I'd feel glad if he'd talked to me for another minute. And even though he didn't stay long, you know, he made me feel good.

Mr. Martin also had a great deal of confidence in his doctor although he said at the beginning, seven years earlier he used to get pretty frustrated by not being told what was happening. This persisted until he discerned that his doctor only gave him information about his illness when he was very certain about the cause and treatment of his health problem.

- Mr. Martin So oh, I've been, they've been running me through all kinds of tests. And I don't expect to see the doctor at all until all these tests come in and he analyses them and digests them and then makes uh. Because he's the type of doctor that won't lead you astray, and he won't tell you anything until he himself has made up his own mind what uh..
- ER And you're very comfortable with that?
- Mr. Martin I, at first, I was very frustrated because I didn't know what was going on. And uh, having talked to people that uh, are patients of this doctor, they'd say, don't rock the boat. You've got the best guy in the market. But he will frustrate you because he won't tell you anything until he himself is satisfied that what he does tell you is going to work. So, after seven years I'm.. I've kind of gotten used to it. *(laughter)*

Mr. Martin alluded to the confidence he had in his specialist when he told me more about how his diabetes was discovered through the careful monitoring and watching. He felt this attention to detail characterised his specialist's approach to his care.

Mr. Martin Uh, that uh, for ah, because he monitors me. Oh he watches me like a hawk and uh, so we got into a discussion and uh, he was asking me how I was feeling and everything like that.

Both Mr. Martin and Mr. MacKenzie had recently been to see their specialist doctors for scheduled visits. Both had been experiencing worsening of their heart failure symptoms, had confidence in their specialists who they saw on a regular basis, and had been admitted to the hospital in order to have their medications adjusted in a controlled environment. Neither experienced any uncertainty about whether or not to go to the hospital. Mr. Martin did experience uncertainty about his illness and treatment initially due to underlying frustration with his doctor.

Consequences of Uncertainty about Going to the Hospital

As a consequence of not knowing what was happening to her on the night of the first of her three recent hospitalisations for heart failure, Mrs. Roy called upstairs to her granddaughter. At this point the accounts of what happened that night differ somewhat, although both Mrs. Roy and her granddaughter concurred that the acute illness episode happened on a stormy night in February. Their recall of the events of the acute episode varied in that Mrs. Roy said her granddaughter called the ambulance and then called Mrs. Roy's daughter. Furthermore, in relating what happened that night she did not tell me that she had been reluctant to call the ambulance whereas her granddaughter said she was.

Mrs. Roy The first time, my daughter was at the camp (*summer home*), in February. She was at the camp and I was with my granddaughter. So, I called her, Sara, come down. Gramere is sick. She come down at once. She know I was sick because I was all wet. OH, MY GOD! ..So she called the ambulance right away and after that, she called her mom. There was a storm that night.

However, the granddaughter related a slightly different account of the events of that night.

- ER So, when your grandma was sick in February, you were here with her by yourself? Do you want to tell me a little bit about that. What happened?
- Mrs. Roy-GD Well, I was upstairs and she called about 12:30 p.m. I guess and she said come downstairs. I can't breathe. I can't breathe and she said, "I need my pump or something." Then, I couldn't find it anywhere. So, then I called my parents and they said, "call the hospital". So, I called the ambulance and they came.

Later during our conversation about what happened that night Mrs. Roy's granddaughter said that her grandmother didn't want her to call either her mother or the ambulance.

- Mrs. Roy-GD She didn't want me to call the ambulance or anything.
- ER Yeah. Did she want you to call your mom?
- Mrs. Roy-GD No.
- ER No? She wanted you--the two of you to figure out what to do here?
- Mrs. Roy-GD Yeah.
- ER Why do you think she didn't want you to call?
- Mrs. Roy's-GD I don't know. I guess she didn't want to worry my parents or something. I think. Or, because they were at camp. And it was that day, it was really, really, stormy.

As illustrated by the comments in the following two excerpts, both her daughter and granddaughter said several times on separate occasions that they believed that if Mrs. Roy had been alone she would not have called the ambulance.

- Mrs. Roy-GD Well, she needs someone to be with her, cause you never know, cause I know if she's by herself, she won't call 911 or anything like that.
- Mrs. Roy-D Like, I don't know if she needs somebody all the time. But, you know, like it happened so fast. Like so far, it happened at night. We were always around but and I know my mother. She won't call for help right away. Like, she thinks she'll be okay, you know. Like, the last time we were at camp and she said, "I'll be fine" and I said, I know you. But, she said, it's going to go away cause she had taken two puffs of nitro and she was taught you know...and I said, well, we're far away here. Like, we can't wait. So, you know, I had to bring her in. But, like if she's by herself, I know she's going to wait. She's not gonna, you know, call for help right away.

Mrs. Roy's daughter and granddaughter gave various reasons why they believed she would not call for help including: not wanting to cause worry, the

weather conditions (stormy night), and Mrs. Roy thinking she would be okay.

Conflict over the action to take when symptoms occurred was evident between Mrs. Roy and her daughter. Furthermore, Mrs. Roy's daughter and granddaughter were both distressed and worried about leaving Mrs. Roy alone because they thought she would not call for help right away.

Uncertainty after Hospital Discharge

Analysis of the data revealed that patients and family members experienced uncertainty after being discharged from the hospital. For patients and their families uncertainty after being discharged from the hospital arose concerning what to expect after being discharged from the hospital, living arrangements and finances.

Uncertainty About What to Expect After Hospital Discharge

Mr. Peterson was a 50 year old man who had been hospitalised twice during the previous month for heart disease. On his first admission he was diagnosed as having had a heart attack. Subsequently, he experienced an episode of shortness of breath and was hospitalised with a tentative diagnosis of congestive heart failure. Both Mr. Peterson and his wife expressed a great deal of uncertainty about what he should or should not be doing at home following discharge from the hospital. This is illustrated in the following excerpts taken from interviews with Mr. Peterson, Mrs. Peterson, and from their family interview. Also as illustrated in the excerpts below, conflicting advice from friends, doctors, and nurses and lack of specific information both were identified as having played a role in the uncertainty about his activity levels after discharge.

Conflicting advice and lack of information. Conflicting advice was received from friends, as well as from doctors and nurses. Mr. Peterson was bombarded with advice from non-medical sources. The advice given by some contradicted that given by others leaving him in a quandary as to what to do. The following excerpt illustrates the different advice given to him by lay people and his resultant confusion.

Mr. Peterson But like, this was the big thing that bothered us. Like, we didn't know at home should I be, oh, you know. Lots of people say, oh exercise! You should be walking every day walk, walk, walk. Should I? Shouldn't I? I don't know, you know. Some people say well, it's okay to walk up and down the stairs. Others say don't, you know? So, really you don't know what to do.

After his first hospitalisation he received no information describing activity levels after being discharged from the hospital and the advice that he had received from professionals was contradictory. The receptionist at doctor's office had said to wait until he saw the cardiologist before going to the cardiac rehabilitation programme. Then, the cardiac rehabilitation programme nurse phoned and said no, you should be coming to the programme. Conflicting directions from the cardiologist's office and the cardiac rehabilitation programme led to further confusion and uncertainty about what to do. Again, as illustrated in the following excerpt, Mr. Peterson was in a quandary about what to do.

Mr. Peterson Nothing to say I should do this, or do that, or whatever. So, then we said, well, what about rehab? So, I had called. The wife had called. And uh, we were trying to figure out should I go or should I not go. So, we called the doctor's office and he said, well the receptionist said, I presume she went and talked to him, and said he'll re-evaluate you when he sees you. So, that was to be last week. This is when I was supposed to see him. So, we left it at that. And then meanwhile we have a call saying, oh no, you're supposed to be in here (*cardiac rehabilitation programme*). So then, that's where the confusion came in.

Mrs. Peterson related a similar story about the difference between what the nurse in the hospital had said and what their temporary family doctor said.

Mrs. Peterson He says, he's getting a better idea but I find that it's worse than it was when he left the hospital. Of course, what he can and what he can't do. Because, I found the nurse told me that to just take it easy, don't do too much. And the doctor at the clinic, when he went in for his check said do whatever you want to do, as long as you don't get tired. That's too much of a difference.

One of the consequences of being uncertain about what to expect or what to do after being discharged from the hospital was expressed by Mr. Peterson as "well, I would say that it is. It's scary. You know, it's scary. You've never been through this". His wife expressed similar feelings when she said:

Mrs. Peterson So it's been, like I found. Anyways, it's been kind of a confusing, sort of ah, you know, but we're going along.
ER Um hum. It's scary?
Mrs. Peterson It is (*emphatic*). Like it's REALLY SCARY, REALLY!

Mr. Peterson also said that not knowing exactly what he should do led him to wonder if he was hurting himself.

Mr. Peterson Exactly, exactly what should I do? What should I be doing, you know. You wonder are you hurting yourself? Or are you (*voice trails off*).

He simply wanted to know what to expect and gave me the example of his pharmacist who provided him with information on everything.

Mr. Peterson So you know what to expect and uh, you know if something does come up. Yeah, like the druggist now, they always give you a sheet on everything.

Mrs. Peterson described not knowing what to expect or do as being hard on them. As well, a hint of family conflict also came through because they disagreed on his activity levels. She talked about having to watch herself so that she was not on his

back all the time. She also said she tried not to be “too overpowering”. These comments emerged during the family interview at home.

Mrs. Peterson So, its' really been hard for both of us. He continues to do a little bit more which I think some of the things he does he shouldn't be doing and but (*laughter*) he sneaks them anyways. I try not to be on his back all the time.

Later on during the interview Mrs. Peterson again stressed the importance she placed on trying to balance keeping Mr. Peterson from being over-active with not being overpowering.

Mrs. Peterson We can laugh about it because you know. But, I know I have to really watch because it's him that's going through it, not me. You know. Not be too over overpowering.

Mr. Peterson told me that his younger brother was also in the hospital at the same time as him. His brother was being treated for rejection of his six year old heart transplant and his prognosis was not good. Perhaps this added to the emotional turmoil experienced by this family. This family was confused and uncertain about the amount and type of activity that could be undertaken by Mr. Peterson after his discharge from the hospital. This family needed clear, specific instructions about what to do and what to expect following discharge from the hospital. The consequences of uncertainty for them were being scared, experiencing family conflict, and confusion about Mr. Peterson's activity levels. Mrs. Peterson expressed concern about balancing being too overpowering with watching his activity levels.

Uncertainty about Living Arrangements

Uncertainty about living arrangements arose as a concern for two patients, Mrs. Roy and Mrs. Pageau. Family conflict rose as a consequence of this uncertainty.

In Mrs. Roy's case she wanted to continue living in the granny flat in the basement of her daughter's home as she had been doing prior to her hospitalisation. She wanted to continue to walk in the garden, visit with her friends, and go with her daughter and son-in-law to their summer home. By contrast her daughter was in a quandary about what to do. She and her husband worked during the day and she was afraid to leave her mother alone. She was afraid that if something happened when her mother was alone that she would not call for medical help. She was afraid of being held responsible by other family members if something happened when Mrs. Roy was alone. She wanted to keep her at home but at the same time she wanted her to move into a nursing home where she could be watched.

Mrs. Pageau's concerns centred on uncertainty about what would happen in the future. Prior to her hospitalisation she had lived alone in a small basement apartment that could only be accessed by stairs. She interpreted the information she had received from doctors and nurses to mean that she could no longer live alone. She did not want to impose on any of her sons for fear of destroying the good relationships she had with them. She knew she could not live alone and was uncertain and worried about who would care for her after she was discharged from the hospital.

Mrs. Pageau	Uh, you know the way they're talking it's gonna take me a long time to get home.
ER	Um hum, um hum.
Mrs. Pageau	So, what happens all this long time I'm gonna get on my feet? I can't expect my kids to come over and clean my house and do my cooking.
ER	Um hum.
Mrs. Pageau	And I sure can't afford anybody.
ER	So it's a worry what (<i>Mrs. Pageau interrupts</i>)
Mrs. Pageau	It's another worry on top of the one you already got.
ER	Yeah, worrying about your health but then (<i>Mrs. Pageau interrupts</i>)
Mrs. Pageau	Worrying about how you're gonna handle.....
ER	Manage?
Mrs. Pageau	Manage it, too. In money wise, it won't be too bad. See, cause I got my husband's Canada Pension and it's six hundred and something and a hundred and thirty eight

and then I would get my disability pension. So there would be enough to cover the rent and whatever. It's just who's gonna cover me?

ER So, well that is something that we'll have to find out about.

Mrs. Pageau Find out if you can get somebody to check on you once in a while. Or if there's a place you can move. Like I told to my kids. I says, if there's a place I could move where I do a little bit of my own cooking and things but you got somebody checking on you. Who won't take all my pensions and leave me starving to death.

Financial Uncertainty

Uncertainty concerning financial security arose for some patients and/or their family members, including Mr. Martin, Mrs. Levesque, and Mrs. Pageau. Mr. Martin didn't feel uncertain about his financial status as shown in the following quote.

ER So, the uh, did you retire at 65 or did you take early retirement?

Mr. Martin No, no. I took, I wasn't 65. I left the mining industry and then I went to driving bus and transports and stuff like that. And uh, of course, after the heart attack the ministry of transport wouldn't license me. They let me reduce my license to a G license but they allowed me to keep my air brakes certificate. I couldn't figure out why they did that because I don't know where you can buy a car with air brakes. *(laughter)* So, I voluntarily dropped that. But uh, no then, that's when I, the heart attack was in 89. I didn't turn 65 until uh, well I'm just 66 now. So uh, but as soon as I got or had this major heart attack, well, I just couldn't work anyway. Ah so, ah, the doctor uh, got me a disability pension and uh, that helped us survive.

ER Yeah well, part of the problem with chronic illness is the financial strain?

Mr. Martin Yeah, yeah the financial burden.

ER So, you're managing all right?

Mr. Martin Oh yeah, fortunately my wife was, she had a good job with the government. So we paid off our house.

However his wife had a slightly different view of their financial situation. When I asked how they were financially she answered "on the, on the edge, you know, just that" and then went on to say "oh, yeah, we own the house, so, we'll survive." Although they both used the word "survive" he had a more cheerful tone in his voice and was smiling as he spoke, whereas when Mrs. Martin said "we'll survive" she did so with a worried look on her face conveying that she felt more as though they were in a financially insecure position. She talked of being "on the edge"

and was not laughing or joking when she said “we’ll survive” whereas Mr. Martin laughed. The subject of financial burden arose again during the family interview when the cost of medications and how they were covered came up as a topic of discussion. Up until he reached 65 years of age, Mrs. Martin’s work drug plan covered 80% of his \$1,000.00 monthly medication bill. Since retirement he was only required to pay the first \$100 for the year. After that all he had to pay was a small prescription fee of two dollars for each prescription. However, he couldn’t work at all after his heart attack and his disability pension was minimal. If Mrs. Martin had not returned to work they would have been in a very difficult financial situation. At the time of his first heart attack she was 63 years old, an age when most people are contemplating retirement.

Uncertainty about the Future

Uncertainty about the future revolved around two issues, when and how death would happen. Some patients and/or their family members talked about uncertainty related to dying. Some patients did so openly while others did not speak of dying at all. Similarly, some family members talked openly about the patient dying while others did not raise the topic. Uncertainty about dying was not a topic in my interview guide but if patients or family members raised the topic, then I listened to what they had to say and encouraged them to talk about what they thought and felt.

Knowledge of prognosis varied considerably between patients, as well as between patients and their family members. In one case, the doctor had told Mrs. Roy’s daughter that Mrs. Roy’s condition had deteriorated significantly such that her heart was now functioning at 25% of normal capacity and that she could die at any

time. Mrs. Roy's daughter worried that her mother did not realise that her illness was terminal. When I asked Mrs. Roy's daughter what the doctor had told her about her mother's illness, she responded by telling me about the amount of damage done to her mother's heart. The information that she had about her mother's prognosis was somewhat vague as illustrated in the following excerpt.

Mrs. Roy-D. Well, the doctor told us, like two years ago. Like, they told us that she had 39% of her heart functioning and the doctor said that it was less then 25% now. Like, they didn't do the big test there. But he said every time this happens it does damage the heart. So...that's about all he said.

At a point later in the interview, she returned to the topic of her mother's prognosis by saying "she doesn't have very long to go" which seemed to be an indirect way of talking about dying.

Mrs. Roy-D Like well, the doctor told us that she doesn't have very long to go. But I don't think my mother realises. GEEZ that's it. She want's to come back here, you know, keep on doing what...

Mrs. Roy's heart function was very, very limited and her daughter left me with the impression that she thought her mother could die at any time. This impression that was confirmed by Mrs. Roy's granddaughter who answered my question about the impact of her grandmother's illness on the family by saying:

ER Would you say there's been an emotional impact on your family from your grandma's illness?

Mrs. Roy-GD Yeah. Like it's really scary. You know that she's going to die but not when, you know. I think that's part of it.

In the excerpt below, during a conversation about whether or not Mrs. Roy should go to her daughter's summer home, both Mrs. Roy and her daughter referred

to there being “no guarantee” and that “something is going to happen”. During the taped interview neither Mrs. Roy nor her daughter openly discussed her possible death. However, prior to beginning the taped interview with Mrs. Roy’s daughter, she did express her uncertainty and fears about her mother dying. Her expressed uncertainty was about not knowing when that would happen and being afraid that Mrs. Roy would be alone at the time.

Mrs. Roy-D	But the doctor said today like there's no guarantee like you know...
Mrs. Roy	Like you say there's no guarantee, here or at the other place (<i>camp</i>).
Mrs. Roy-D	Well, I know. Something is going to happen and...
Mrs. Roy	There's no guarantee, it doesn't matter where.
ER	Yeah. So you may as well enjoy.
Mrs. Roy	Yeah. That's what I said.

Another study informant, Mr. MacKenzie, began talking about dying before I even had a chance to begin his interview. First he recounted the events surrounding his wife’s death and then he spoke about his own uncertainty about dying. Mr. MacKenzie, a patient in the intensive care unit when I interviewed him, had been told he had six months to live. For Mr. MacKenzie, uncertainty revolved around a concern for “how am I going to die”. The excerpt below illustrates this patient’s uncertainty about dying. For him, uncertainty centred not on when or if he would die, but rather on how he would die.

Mr. MacKenzie	I don't blame any heart doctor, for this (<i>touches his amputated leg</i>) you know. I might blame the foot doctor, you know, for letting that go from a little simple cut. But my biggest problem is, how am I gonna die.
ER	Um hum. Um hum.
Mr. MacKenzie	Not if I'm gonna die. I'm a good Christian. It's how I'm gonna die? I'd be glad to leave tomorrow.

Later on during the interview this patient again drew my attention to his concerns about how he was going to die. He went on to tell me:

- Mr. MacKenzie I'm worried mostly, how I'm gonna leave here. I had a few experiences of choking and uh, that's not a pleasant uh.
- ER Feeling?
- Mr. MacKenzie You know, even to the point of thinking what can I do to avoid the inevitable, you know. I, as much as I can do about suicide, you know. It's really in your head.
- ER Yeah, sure it is.
- Mr. MacKenzie OOOOH!
- ER Have you talked to the doctor about it at all?
- Mr. MacKenzie About what?
- ER About the feelings you get when you're choking or having real difficulty breathing?
- Mr. MacKenzie Well, he knows I have a hard time breathing. I made out a written will already. I talked to the nurse a little bit about it. She told me to give a copy of it to the doctor and to your heart specialist which I didn't, you know.

This man had very vivid memories of his wife's terminal illness and death. He, his son, and daughter had cared for her at home for a year and a half while she slowly died of throat cancer. She had a tracheotomy and required regular injections of pain medication. Little or no support was given to them to help manage her illness at home or to deal with her last days in hospital. She was hospitalised for the last 17 days of her life and during that time she simply stopped eating. Consequently, his uncertainty centred on how he would die, not if, or when he would die.

In the case of Mr. Martin it was his wife and son who expressed uncertainty about dying. Mr. Martin did not really express uncertainty about dying. In fact, he only talked about dying when he related the events of his first heart attack. His wife was uncertain about whether or not her husband realised how ill he was, whether or not he knew he was dying. She also expressed uncertainty about what was going to happen next. After having introduced myself to her and describing the study she interrupted my first question before I had finished speaking and said:

Mrs. Martin Well, he's, his feet have swelled up so much and they don't seem to be going down.
ER Um hum.
Mrs. Martin And well, of course, there's, I know from past experience with my mother and all, that, I know, that, when their feet swell up like that its sort of towards the end.
ER Uh huh, is ah, do you (*interrupts before I can finish my question*)
Mrs. Martin I don't think that he realises this. Of course, the doctor hasn't given us very... given us very much hope, either.
ER Um hum.
Mrs. Martin I don't know how much he (*Mr. Martin*) knows and I don't say anything.
ER Have you talked to the doctor yet?
Mrs. Martin Well, all he told me was that he was a very sick man and uh, don't expect too much (*voice trails off*).
ER Uh huh?
Mrs. Martin You know? What can you do? (*voice tearful. Abruptly stands up and as she leaves the room she asks*) Will you have some coffee?

She believed that the change in his symptoms to now include swollen feet heralded his imminent death. She based the interpretation of this new development of swollen feet on past experience with her mother who also had heart problems and who died after developing swelling of the extremities.

When telling me about his prognosis Mrs. Martin talked first about thinking he wouldn't "make it" after his first heart attack. She then revealed a shift in her thinking to likening trips to the hospital to "going in for a check up". Uncertainty arose when she said she was "always wondering what will happen next" and described herself as "being on edge". However, she also talked about always being "optimistic" and "going along with our lives".

ER What kind of an impact would you say his illness has had on your family as a whole?
Mrs. Martin Well, you know when he first had the heart attack we didn't think he was going to make it and then you know he got better from that and he's been in the hospital so many different times. Like my son says, he goes into hospital every once and a while just for a check up. (*Laughs*) Just to get, you know and he seems to be fine. But I don't know, this time it doesn't seem to be working that way. We've always been very optimistic about it.
ER Uh huh, um. Has it changed, I guess the real big change probably came in 1989 with the uh..
Mrs. Martin Yes, when he had the big heart attack.
ER Yeah and since then things have sort of settled into a routine?
Mrs. Martin Um hum um hum.

ER Do you think there has been an emotional impact on you or on your son or on your daughter?
 Mrs. Martin. Well, to a point because we're always on edge wondering, you know, what's going to happen next. But we all still go along with our own lives and keep busy and uh..

Mr. Martin's son expressed uncertainty about his father's prognosis. He said he had not been told much about his father's prognosis and what little information he had received from doctors varied greatly—ranging from two days to live after his father's initial heart attack to two years at a later date.

ER Yeah, so what do you think of his prognosis? What's your perception of how he's doing?
 Mr. Martin-S What's his prognosis is a really good question. Uh, we don't get told very much at all! We assume little bits. We assume when the doctor says cancer of the lungs and he's a very sick man and this sort of stuff. Well, I can think of one time, one of the doctors said, you know, he had two years.
 ER Um hum.
 Mr. Martin-S But then they told us, he may have only a couple of days back in '89. So, you know.
 ER Yeah the uncertainty of it?
 Mr. Martin-S Yeah.
 ER Pretty difficult.
 Mr. Martin-S Yeah, I mean this is the, probably one of so many bouts or relapses or whatever you want to call them he's had. This is one of the worst. He hasn't bounced back as well as he normally does.

In the interview with Mr. Martin's son, he said he and his sister wanted to know their father's prognosis and that his mother, Mrs. Martin, did not and that this had frequently been a topic of discussion and disagreement amongst the three of them. In contrast to the uncertainty revealed in conversations with his son and wife, Mr. Martin never expressed the same sort of questioning and wondering about his frequent trips to the hospital or about his worsening symptoms. Uncertainty was preferable to bad news for some family members but not for others.

Properties, Conditions, and Consequences of Uncertainty

Properties of uncertainty for the ill person included the unanticipated, unexpected onset of symptoms, the ambiguity about what symptoms meant, apprehension about feeling ill and not knowing the cause, indecisiveness and confusion about what action to take when symptoms occurred, fear of what is going to happen (fear of the unknown), the unpredictability of the future occurrence of symptoms, and the unpredictability of prognosis.

Conditions that contributed to uncertainty involved characteristics of the illness specifically, further sudden deterioration of the person's heart condition resulting in hospitalisation, patient and family lack of knowledge or understanding of the meaning of symptoms and the action to take to deal with them, phase of illness, and prognosis.

The consequences of uncertainty encompassed family interactions characterised by conflict, distress, agitation, fear, anxiety and frustration, and individual family member's anxiety and fears about the unknown. Patients and family members did not necessarily experience the same emotions. Differences in emotional responses affected family relationships and reverberated throughout the family.

Summary

Uncertainty occurred in relation to three different topics. First, uncertainty occurred in relation to patients and family members being unsure about the meaning of symptoms which was then linked to decision making about whether or not to go to the hospital when acute illness events occurred. Uncertainty was also evident regarding expectations about physical, social, and emotional activity after discharge

from the hospital. Uncertainty about the future included questions about when and how death would happen and was a concern expressed both by patients and family members. Uncertainty resulted in various emotional, social, and physical consequences for both patients and their family members. Uncertainty contributed to family interactions (conflict and confusion) and illustrated the impact of the ill family member on the family and the family on the ill family member.

CHAPTER 7

FAMILY RESPONSIBILITY

Family responsibility emerged as a major category through an analytic process, similar to that used to uncover uncertainty. Early on in the process of analysing the interactions between patients and their family members, changes in living arrangements, daily activities, and relationships were revealed. In order to develop a deeper understanding of these changes, questions were incorporated into later interviews to explore and clarify how decisions to make changes in living arrangements, daily living activities, and relationships were made as a consequence of illness. I then explored how patients and their family members responded to these changes. Changes in living arrangements and changes in daily activities and relationships eventually evolved as substantive subcategories of the major category or concept, family responsibility.

I used constant comparison to compare data with data, and category with category. Comparing data with data involved the comparison of different patients' and family members' behaviours and their accounts of family changes through the use of four questions:

- 1) What illness connected changes happened to patients and their families?
- 2) What conditions precipitated these changes?
- 3) How were decisions to make changes in patient and family living arrangements, roles, and activities made ?
- 4) What were the consequences of changes for patients and for their families?

As discussed in Chapter 4, a conceptual category can be developed from substantive categories by determining whether the substantive categories are properties, conditions or consequences and by identifying how a conceptual category changes and relates to other categories. The identification of properties, conditions, and consequences helped to develop the conceptual category, family responsibility, while at the same time ensured that family responsibility was grounded in the data. I used the following questions to examine the data to decide what the properties, conditions, or consequences of family responsibility were:

- 1) What were the characteristics of family responsibility?
- 2) Under what conditions did family responsibility occur?
- 3) What were the consequences of family responsibility?
- 4) What factors, behaviours, and actions contributed to family responsibility?

In the following pages, I will show how the concept of family responsibility emerged and was developed from the data. I will do so by delineating the properties, conditions, and consequences of the substantive categories, changes in patient and family living arrangements and changes in patient and family activities of daily living and relationships. Delineation of these substantive categories led to the development of a major category or concept, family responsibility.

Changes in Patient and Family Living Arrangements

Changes in the living arrangements were experienced by several patients and their families including Mrs. Roy, Mrs. Pageau, Mrs. Brunette, Mr. MacKenzie, and Mrs. Levesque. How and when decisions to change living arrangements were made

and some of the consequences of such moves were considered as the data were simultaneously collected and comparatively analysed. Uncertainty about what might happen to the patient if he/she lived alone or in an unmonitored situation often combined with physical limitations imposed by deteriorating health status tended to precipitate decisions to make adjustments in living arrangements. Also, living arrangements were changed to facilitate the giving of medications and to limit physical activity such as, doing household chores.

How the decision to make changes in living arrangements was made varied from family to family. Sometimes these decisions were made by the patient, sometimes they were initiated by the main caregiver, and sometimes the decision was influenced by all family members. For some family members changes in living arrangements led to emotional upset characterised by crying during the interview, descriptions of feeling bad and depictions of conflict amongst family members. Whereas, for other families changes in living arrangements were accompanied by both gains and losses for the patient. Some changes in living arrangements were viewed as necessary because of patient acknowledgement that physical functional losses rendered the patient unable to live alone. For some patients changes in living arrangements were welcomed as an opportunity to strengthen existing warm relationships. For some family members changes in living arrangements were described as being stressful. For many patients and families who made changes in living arrangements there was an attempt to maintain or resume 'patterns' of living that had existed prior to hospitalisation.

Mrs. Roy and Family

The first family unit to be analysed within the context of changes in living arrangements was that of Mrs. Roy, whose history and circumstances were described in Chapter 5. During my hospital interview with Mrs. Roy when I asked her where she lived, she replied matter of factly that she lived in a granny flat in the basement of her daughter's home. Since her response did not indicate that housing was a concern, I moved on to the next topic in the interview. In a subsequent interview with Mrs. Roy's daughter, it became apparent that where Mrs. Roy would live after discharge from the hospital was an issue of great concern for Mrs. Roy's daughter. Mrs. Roy's daughter was the central figure in the Roy family account of living arrangements. She expressed considerable anxiety over the dilemma of where her mother would live after she was discharged from the hospital and talked about moving Mrs. Roy into a nursing home. In contrast, Mrs. Roy wanted life to continue as it had before her hospitalisations. She wanted to return home to her granny flat in the basement of her daughter's home. During the hospital interview she did not mention the possibility of moving to a nursing home. Mrs. Roy's daughter worried about what might happen if she left her mother alone either during the day while she worked or during the weekend when she was away at her summer home. As well, she expressed feeling torn between caring for her own daughter (Mrs. Roy-GD) and caring for Mrs. Roy, her mother. Ultimately she said that she was primarily concerned with preserving her daughter's health and her daughter's right to lead her own life. As described in Chapter 5 Mrs. Roy's granddaughter had a history of Crohn's disease. Consequently Mrs. Roy's daughter did not want to leave her mother

(Mrs. Roy) alone with her daughter (Mrs. Roy-GD) because she felt it was too stressful for her daughter. Mrs. Roy's granddaughter (Mrs. Roy-GD) had been so distressed after her grandmother's first episode of acute illness that she was in an automobile accident the next day. As the following excerpt shows, the granddaughter said the car accident happened because her attention had been distracted from driving by thoughts about her grandmother's illness event the night before.

ER How about you, yourself. Has it affected you in any way?
Mrs. Roy-GD. Why, the first one did, yeah. I was really scared. And afterwards a day or so later I was driving my car and well I was just... I was thinking about her and I wasn't concentrating at all on the road and then I hit another car.

Mrs. Roy's daughter felt that the only solution to the dilemma of taking care of Mrs. Roy was moving her into a nursing home as illustrated at the end of the following excerpt.

Mrs. Roy-D Well, she (*Mrs. Roy's granddaughter*) goes to school at the university and she's working now, two jobs in the summer. So, you know, I can't depend on her to take care of my mother. Like, I mean she's got her life too! And, and she was with her the first time, in February. She's the one that called the ambulance. Like it was, she took it really hard, like and then my daughter is sick too, so...she's got Crohn's disease and...you know, like, she doesn't need a lot of stress for her.
ER So what have you been thinking about how to handle this?
Mrs. Roy-D Well, I talked to my mother about putting her in a nursing home. And she said she would. But I mean, she told me yesterday to go and make the appointment.

During the interview with Mrs. Roy's granddaughter when I asked where her grandmother would be living after she was discharged from the hospital, she thought that Mrs. Roy would be going to a nursing home and she suggested that it would be a "good" move". She rationalised that in a nursing home Mrs. Roy would not be alone.

Mrs. Roy-GD Uh, huh. She thinks that she's going into a nursing home or something.
ER Uh, huh. What do you think?
Mrs. Roy-GD Well, I think that would be good too! Well, I don't want her to leave here! But like, she could always come here whenever she wants. It's just that during the day and at night if we're not there she would have someone with her.

Mrs. Roy's daughter's anxiety and guilt was evidenced by the tears she shed while talking about the proposed move to a nursing home, her reference to worrying

about leaving Mrs. Roy alone during the day or night, and her words “I feel so bad” as illustrated in the following excerpt. The sense of being responsible for what might happen to her mother while she was away was repeatedly voiced by Mrs. Roy’s daughter during the interview.

- Mrs. Roy-D Anyway, I asked my mom if she’d want to put her name at (*nursing home*).....it’s not because I don’t want to keep her. It’s just, like I’m worried. Like, you know, I go to work and I’m worried and...if I go out at night and some days I go somewhere I’m always worried that, you know, something could happen to her and there won’t be anybody here and she won’t call for help. So, I told her, you know, at least there (*at the nursing home*), like it’s just two minutes away...
- Mrs. Roy-D I feel so bad.

Later on during the interview Mrs. Roy’s daughter again returned to the topic of living arrangements indicating that her sister was supportive but couldn’t help much because she lived several hundred miles away. Her brother, on the other hand, lived nearby, however, he was depicted as not being particularly helpful. Mrs. Roy’s daughter’s emotional distress became even more apparent when she broke down and began to cry during this part of the interview.

- Mrs. Roy-D My sister is very supportive. But my brother, well, so, so. He’s just an hour away from here. Like, when I told my mom yesterday, and while we were talking and he was there and my mom’s sister was there and I asked my mom, like about the nursing home (*began crying as she related what her brother had said*).

Mrs. Roy’s daughter found her brother was quite unhelpful and very unrealistic about any contribution he could make towards taking care of their mother. According to Mrs. Roy’s daughter, even Mrs. Roy found her son’s solution unworkable. Conflict between Mrs. Roy’s daughter and Mrs. Roy’s son over the proposed move was evident.

- Mrs. Roy-D And my brother he’s no help being the supporting one. He said, “Well, you can come and stay with us.” Like, you know, AS IF!
- ER It’s going to be any different?
- Mrs. Roy-D Yeah, cause my brother’s retired and so is his wife. But he smokes like a chimney. And my mom said, “well, I can’t take the smoke” Like, you know...
- ER Oh, she would never be okay.
- Mrs. Roy-D No! Well, he said, “Well, we could go smoke outside, us.”

As the interview continued, Mrs. Roy's daughter's frustration and anger with her brother came through strongly in her voice. She said that her brother and his wife had never offered to stay with Mrs. Roy in the past. She couldn't see how he would be able to take care of her now.

Mrs. Roy-D YEAH, WELL GEEZ! He can't even come and stay with her for a weekend! So I can have a weekend off. How is he going to take care of her?

Mrs. Roy's daughter had decided that a nursing home was the long-term solution to the dilemma of who would stay with Mrs. Roy during the day when she was either at work or away from home. In the meantime, Mrs. Roy's daughter expressed the need to find someone to stay with her mother as an interim solution until a move to the nursing home was possible.

Mrs. Roy-D Yeah. Well, like, I'd like to know if there's anybody that you can hire.
Somebody like to come and stay with her or...
ER Uh, uh. During the day when you're gone? Yeah, so she could stay here.
Mrs. Roy-D Well, I mean, she said she would put her name at the nursing home. But I mean,
you don't get in there like overnight.
ER No. You're going to have to figure out...
Mrs. Roy-D There is a long wait.
ER Yeah.
Mrs. Roy-D A lot of things could happen in the meantime. But it's something that has to be
done. She said yesterday, well, I know, I have to do it.

Again, her feelings of anxiety were evident as she related to me how she had told her mother that she wished she didn't have to work. Mrs. Roy's daughter saw the illness as "just as bad as cancer". She felt trapped and unable to do anything.

Mrs. Roy-D Because it's just as bad as cancer, you know. You're stuck you can't do anything.
ER A support service, especially if people want to be maintained in their own home,
needs to be...
Mrs. Roy-D Yeah, like I was telling my mom, like I wish I could, you know, quit my job and
that, but I can't.

The decision to have Mrs. Roy moved to a nursing home was her daughter's idea. Mrs. Roy's daughter had previously talked about such a move with Mrs. Roy but she had not discussed such a possibility with her sister or her brother until the subject

came up during a family visit at the hospital. Mrs. Roy's daughter had discussed the possible move to a nursing home with her own daughter, who thought it was a good idea.

For the family unit interview, I interviewed Mrs. Roy and her daughter in her daughter's home four weeks after she had been discharged from the hospital. At that time she was once again living in her granny flat in the basement of her daughter's home. Mrs. Roy's daughter had worked out some strategies to deal with her concerns about leaving Mrs. Roy alone while she was at work or away at the weekend. Mrs. Roy's daughter had acted on information that I gave her after the first interview with her when Mrs. Roy was still hospitalised. Consequently, Mrs. Roy's daughter had contacted a volunteer palliative care resource available to patients like Mrs. Roy. Assessment by the palliative care social worker resulted in arrangements for volunteers to come in and stay with Mrs. Roy three times a week. Mrs. Roy's other daughter found and hired a woman to stay with Mrs. Roy on those weekends when she would otherwise have been alone.

During this family interview Mrs. Roy's daughter continued to express uncertainty about whether or not Mrs. Roy would call for help if she was alone and experienced symptoms requiring medical intervention. Mrs. Roy's daughter said that when she was at work she called home several times during the day to make sure her mother was okay. The behaviour of checking up on her could be viewed as vigilance, keeping an eye on her making sure she is okay. The topic of the need for Mrs. Roy to move into a nursing home did not surface at that time. However, Mrs. Roy made it quite clear that she wanted to continue living the way she had before she was hospitalised whereas her daughter continued to be hesitant about leaving her

alone. For example, Mrs. Roy reiterated her wish to go to her daughter's summer home to which Mrs. Roy's daughter responded in a reluctant voice, "I guess we'll have to take her".

Mrs. Roy's daughter experienced fear, guilt and a sense of responsibility. She saw moving her mother into a nursing home as the solution to her dilemma. Mrs. Roy's daughter said "But the doctor said, today, like, there's no guarantee, like you know". Mrs. Roy interrupted and said "There's no guarantee, it doesn't matter where" and although she never verbalised opposition to moving into a nursing home during the family interview, she repeatedly expressed the view that everything was fine just as it was. The granddaughter's words reflected Mrs. Roy's daughter's fear of leaving Mrs. Roy alone.

ER	Would you say that having your grandma sick has affected your family in any way?
Mrs. Roy-GD	Well, somewhat, I would say. Well, for my parents they're always worrying that they don't want to leave her alone.

In the context of this family, the illness of one individual had an impact on the whole family system.

Changing living arrangements was never openly addressed by Mrs. Roy in the final family interview. However, characteristics of her personality influenced decisions that were made about living arrangements. Mrs. Roy had a matter of fact, down to earth, determined, fatalistic way of talking about her health and what the future held for her. She was ready to compromise, to rest, to follow directions and she was armed with information about what her symptoms meant, and promised her daughter that she would call for help if anything happened while she was at home alone. She wanted to remain living in her daughter's home, to maintain past patterns of living such as going to camp with her daughter. Mrs. Roy's daughter on the other

hand unilaterally decided changes in living arrangements needed to happen and she then attempted to persuade her mother that she needed to move into a nursing home. Mrs. Roy's daughter talked about this proposed change with her own daughter but did not consult or discuss this option with her brother and sister until after conflict arose. The motivation to make changes seemed to be the desire to protect Mrs. Roy from harm.

Conditions that precipitated the decision to make changes in living arrangements were Mrs. Roy's frequent recent hospitalisations and the deterioration in Mrs. Roy's cardiovascular health which led to uncertainty about the future. Mrs. Roy had a fatalistic attitude about the future. Mrs. Roy's daughter felt "stuck" caring for her mother and felt responsible for taking care of and protecting her. Lack of realistic support from Mrs. Roy's son and some support from Mrs. Roy's other daughter, who lived several hundred miles away, were other factors in the living arrangements that evolved for Mrs. Roy.

Mrs. Roy wanted to maintain patterns of living that existed prior to the deterioration of her health. Protective behaviour on the part of Mrs. Roy's daughter focused on finding someone else who could watch Mrs. Roy, in this case a nursing home. The proposed change evoked feelings of guilt in Mrs. Roy's daughter. Family conflict arose. Mrs. Roy's daughter had a tremendous sense of responsibility for the care of her mother that came into conflict with the developmental needs of her family. At this point in family development the the need to promote Mrs. Roy's granddaughter's sense of freedom and independence came into conflict with the need to provide care for Mrs. Roy. Family conflict also arose between Mrs. Roy's daughter and her son over the issue of where Mrs. Roy should live.

Mrs. Pageau and Family

Mrs. Pageau was a 65 year old woman who had a history of heart disease. I interviewed her on her seventh day of hospitalisation for congestive heart failure. The cause of her failure was inconclusive. It might have been due to a possible heart attack that had occurred several weeks prior to this hospitalisation, or by an existing cardiac arrhythmia or by existing mitral valve disease. The source of her failure was never clearly established during the time that I was in contact with her.

Prior to her hospitalisation, she had been living alone in a small basement flat, accessible only by a steep staircase, which she now felt she would no longer be able to climb due to her illness. Her sons felt that a move to another location where she could be watched was a necessity. The doctor reinforced the need for Mrs. Pageau to move. The need for adjustments in her current living arrangements was acknowledged by Mrs. Pageau and by her sons. There was no conflict over the need for Mrs. Pageau to be monitored. There was conflict about the solution of the dilemma of where and how monitoring would happen. The following excerpt taken from the hospital interview with Mrs. Pageau identifies the disagreement that existed about where she would live after being discharged from the hospital.

Mrs. Pageau I want to go home. They don't want me to. What am I gonna do at home? What am I gonna do at his home? Put up with my son and the kids yelling and screaming. That's gonna drive me totally bananas or I'll drive him totally bananas by trying to make him keep the kids quiet.

Later on during my interview with Mrs. Pageau she continued on to say that she could never live with either her oldest or her youngest sons. She said the oldest one had mood swings caused by an old head injury. She also said that the neither of them were very flexible and that they would try to boss her around. In referring to them she said, 'there's no bend'. Furthermore, she expressed concern that if she

lived with her middle son, their good relationship would be destroyed. He was a single parent caring for his ex-wife's daughter from a previous marriage and the two children from their marriage. His ex-wife had left him and the children four years earlier when their baby was four months old. Mrs. Pageau felt there would be great risk of confrontation over noise created by the normal behavior of her small grandson if she lived with this son. The following excerpt highlights some of these concerns.

Mrs. Pageau Um hum. So, you know. And the other one (*youngest son*) goes to school and the other one (*oldest son*) had an accident with a, with a train and left him with nasty headaches. So he's a nasty, cranky little people. So, eh, you know. When you don't feel good yourself and I don't know. We have a good friendship and I don't want to ruin it by going to live with them (*middle son and his children*).

ER Uh hum, uh hum.

Mrs. Pageau And that's it. Like my son says, you know. I says, well, I think I could get a beeper and if something happens to me all what you have to do is press on it and get a couple of phone numbers.

Mrs. Pageau also indicated that she wanted to talk with someone who was not part of her family. She said there were some things that she didn't want to talk about with her family. She went on to say that she didn't want to talk with family members because she thought they would offer solutions that she wouldn't want to accept.

Her need for independence was strongly voiced in the following excerpt.

Mrs. Pageau And sometimes there's things you don't want to discuss with your family.

ER I know.

Mrs. Pageau Like, I mean, I don't want to tell my sister. I'm afraid she's gonna say, well, you're gonna come live with me. Well, I don't wanta live with anybody. You know, if I lose my independence what the hell do I got?

The interviews with two of her three sons revealed the use of similar words and expressions which suggested that they had talked with each other and with their mother about where she would live following discharge from the hospital. In separate interviews, some of the words and expressions used by Mrs. Pageau and her sons were identical. For example, they each made reference to her "independence" and they each suggested that she would be best living with the second oldest brother. The

following excerpt taken from my interview with Mrs. Pageau's youngest son (Mrs. Pageau-S1), shows his reference to her independent nature, her preference for living alone, and her need to be monitored. He also identified the second oldest brother's wish to have her stay with him.

- ER So, um, how do you see your mom managing when she goes home from the hospital?
- Mrs. Pageau-S1 Um. She'd have to stay with somebody--one of us.
- ER Have you and your brothers talked about this at all?
- Mrs. Pageau-S1 My second oldest brother supposedly wants to stay with her.
- ER Okay. What do you think she would think?
- Mrs. Pageau-S1 I think, she is, she hates being um, how to put it there, um, dependent on other people. She's a very independent person.
- ER Uh, huh, and probably always has been.
- Mrs. Pageau-S1 She would much rather live alone and everything. And if we can get her an outpatient place that's uh, monitored or you know, a beeper (*Lifeline*) or something like that, you know. Like, if the doctor told her she could live alone, she would.
- ER How do you feel about that?
- Mrs. Pageau-S1 I think she should live with my brother. But on the other hand whatever makes her happy. Cause the doctor said that uh, if she has another heart attack she's a goner anyway. So, I don't know. It doesn't matter whether my brother is gonna be there or not next time.

During the interview with Mrs. Pageau's oldest son, he also spoke of his mother's desire to be independent. However, he qualified that statement by then saying that independence was not possible. He spoke in a very firm, dogmatic voice which immediately reminded me of Mrs. Pageau's depiction of her sons as 'there's no bend'. The force of his spoken words, delivered in a quick, staccato-like manner confirmed the picture his mother had drawn of a man who would not be flexible, would not bend.

- ER And um, one of the things that I noticed in talking with your mother is that she wants to be able to do what she wants to do.
- Mrs. Pageau-S2 She'd like to be able to be independent, yes. But, no she can't.

Properties of change for Mrs. Pageau included recognition of the conflict between herself and her sons regarding where she would live after discharge. She was depicted as independent by herself and by her sons. Her need for independence

was a factor in deciding where she would live after discharge as was her concern that existing good relationships could be damaged if she moved in with her middle son. For her sons, attributes of change were the need to have information from the doctor about their mother's illness.

Conditions that precipitated the need to look at where Mrs. Pageau would live after discharge included the recent, unexpected death of her husband, her own sudden, unexpected deterioration in her health, and uncertainty about what she would be able to do after discharge. Her sons recognised the need for Mrs. Pageau to be monitored and acknowledged that in the words of one son "oh yeah and we're very protective of her". In terms of decision making Mrs. Pageau and her sons said that the doctor was the person who would tell them what needed to happen after she was discharged from the hospital. Her sons went on to add that they thought that their mother would listen to and follow what the doctor said should be done.

Mrs. Pageau expressed resistance to changing her living arrangements because she feared ruining her relationship with her sons and she feared losing her independence. The developmental needs of her son's family were in potential conflict with her care needs. She was uncertain about whether or not she could live alone because of her physical health. Her sons recognised that she was an independent person but felt that she could not live alone. However, she and one son thought she might be able to live alone if she had a Lifeline (a monitoring device) in her home. Information from the doctor was seen as a critical factor in her decision regarding where to live after discharge from the hospital. Her sons had a need to protect her and saw moving in with one of them as the best way to do this. She feared the loss of

independence if she went to live with anyone. There was potential conflict between her need for independence with their need to watch and protect her from harm.

Mrs. Brunette and Family

A change in living arrangements as a result of her illness also occurred with Mrs. Brunette and her family. Mrs. Brunette was a 75 year old woman who had a 16 year history of heart disease. She had been hospitalised once prior to my first interview with her in the hospital. This admission had coincided with her husband's emergency admission to the hospital where he had died from a heart attack. I interviewed her during her second admission two weeks after the death of her husband. During that interview she was very quiet, had a sad expression on her face, drooped shoulders and a generally 'down' demeanour. She was admitted to hospital in congestive heart failure caused by damage from previous heart attacks and long standing mitral valve disease.

When asked about her living arrangements, Mrs. Brunette matter of factly said that she lived with her eldest daughter and son-in-law. Mrs. Brunette's daughter-in-law confirmed a recent change in living arrangements during an interview later that same day.

ER	And you're living with your daughter right now?
Mrs. Brunette	Live with, my uh, daughter move in with me. My husband just passed away.
Mrs. Brunette-DIL	She's living at home but her, the eldest daughter moved in with her.

The death of Mr. Brunette, who had been Mrs. Brunette's primary caretaker, had precipitated Mrs. Brunette's eldest daughter to permanently move into Mrs. Brunette's home to take care of her. During the interview it also became apparent that the changes in the family extended beyond Mrs. Brunette's daughter and son-in-

law. In fact, her granddaughter had moved home from a metropolitan city over two hundred miles away.

Mrs. Brunette-D She (*Mrs. Brunette*) wanted me to live with her. She didn't want nobody else to live with her. Yah, because we (*oldest daughter and her husband*) did everything, eh. I got my daughter (*Mrs. Brunette's granddaughter*) down south moving in my house, see. That's the first house, the white one. That's where I live. But now, my daughter's gonna move in there.

Mrs. Brunette's eldest daughter indicated that moving in with her mother had caused a big change in her life but that she didn't mind because she perceived Mrs. Brunette as having been a good mother who had led a hard life and deserved to be cared for. Mrs. Brunette's life had been hard because she had 14 children and because her husband had been a violent, alcoholic up until ten years prior to his death. Mrs. Brunette's eldest daughter and son-in-law were in the habit of coming to her assistance when Mr. Brunette became violent. In fact, Mrs. Brunette's daughter had a long history of helping her mother. She had left school when she was only 12 years old in order to stay home and help her mother with the younger children. Mrs. Brunette's daughter said that it was her "pattern" to help her mother, to "take care of her".

Mrs. Brunette-D Yeah, cause it's been a big change for me too, eh. (*Laughs*)

ER Oh, a big change?

Mrs. Brunette-D Yeah, a big change. Yuh, a big change. I don't mind doing it, cause she was there for us when we were kids, you know. She was a very good mother. I was there all my life for her. (*Laughs*). It's my pattern. Always. All the time. She had a hard life. So, I used to come over and take care of her.

Mrs. Brunette's daughter then talked about other changes that she had experienced. She spoke of her emotional response to caring for her mother which was one of fear. She was afraid to leave her mother alone, afraid of what might happen if she left her alone, and afraid that she would be held responsible by other family members if anything happened to Mrs. Brunette in her absence. It was difficult to encourage Mrs. Brunette's daughter to elaborate on her fears because she spoke so

rapidly. I was barely able to ask questions but rather listened to what she had to say.

ER Are there other things that have changed? Things that have happened?
Mrs. Brunette-D Well, I think that I'm scared. I'm scared to leave her alone. Come back and something happens. I'd like be history. See, I won't leave her anywhere cause I'm scared, eh.

Mrs. Brunette's daughter-in-law talked about Mrs. Brunette's daughter's role as "taking care of her" and suggested that Mrs. Brunette's daughter might be "unsure of a lot of things". She then suggested that there were differing opinions inside the family that were causing conflict.

Mrs. Brunette-DIL Um so maybe in that part, yeah. I think, maybe in her oldest daughter's part. She's taking care of her. So, she's got the bulk of everything now. And she might be very unsure of a lot of things, too. And then there might be somebody in the family really headstrong that thinks, you know, that this is what you have to do. And it's wrong. You know.

Mrs. Brunette's daughter had a history of being responsible to help her mother, of being the daughter to come to her mother's assistance—somewhat like the experience reported by Mrs. Roy's daughter.

Mrs. Brunette-D Oh yeah, she is loved. Even my husband. He says that, your mother, you know, yeah. Well, we take care of her all of her life, eh. You get close. So, whether you want it, we used to come when my dad used to beat her up, you know.

ER Um hum.

Mrs. Brunette-D (*nervous laugh*) So I don't mind taking care of her.

At various points in the interview Mrs. Brunette's daughter expressed her fear that her mother would "die on her". She did not want to leave her mother alone because she was uncertain about whether or not Mrs. Brunette would realize when she needed emergency medical help. She also worried whether she would go to the hospital because she had not called for help right away on previous occasions. In addition, Mrs. Brunette had experienced cardiac pain since discharge from the hospital but had not told her daughter. Mrs. Brunette had not recognized when she needed medical help and had refused to take the ambulance to the hospital, a scenario

very similar to both Mrs. Roy and Mrs. Pageau. Mrs. Brunette's daughter also talked about the restrictions of looking after her mother including no longer being able to just get up and go and do whatever she and her husband wanted without first considering her mother. Now, she would have to think about her mother before making plans for herself. She talked about 'having to adjust' to these big changes in her life.

ER Do you think there have been any uh changes? Well, there have been changes in the sense that you've moved in (*Mrs. Brunette's daughter interrupted before I could finish my sentence*).

Mrs. Brunette-D You're not kidding! So, ah that's.... I can't just get up and go no more. You know what I mean? So, I gotta stay here, make sure she's fine and uh, I have to adjust to it, you know. My life is different (*laughs*).

ER Yeah, really different.

Mrs. Brunette-D Yup. Really different, eh. It's a change. I'm not asking for praise, eh.

Mrs. Brunette's daughter said that she thought that her brothers and husband had reacted positively to and felt good about the decision to move into Mrs. Brunette's home. She indicated that her brothers "accepted" and were "happy" and "glad" about the move.

ER How would the change be for others in your family, do you think?

Mrs. Brunette-D My brothers and that? Oh they seem to accept it. They were the ones that were so glad that I moved in, eh. Because with daughters-in-law working, some of them, eh. So, they were so happy.

She then spontaneously described to me how the decision to move into her mother's home was made. The decision seemed to have been initiated by Mrs. Brunette's daughter and according to Mrs. Brunette's daughter the decision was welcomed by Mrs. Brunette and the other members of the family.

Mrs. Brunette-D I come and asked mom, eh. I came over and asked her. Cause they knew this was a panic of two little kids which I take care of all week. Sure and I keep (*babysit*) kids, eh. So, I came and asked her. I said, Mom who do you want to live, I... You know, we (*the family*) know she can't live alone. She said, "You daughter. You or Melvin". Are you sure? So, when she went into the hospital the last time I thought that me moving in with my stuff and that upset her. I think there was a lot of stress there like, too, eh. Like, how she got sick. I thought, maybe that's what brought it (*the illness*) on. I said, Mom if you want me to move out, I'll move out. "No, no", she said, "I don't". Cause if she says, any day that she doesn't want me here, I'll go, you know. But, she said to me, "You've been good to me".

She also indicated that her husband did not mind moving and said that he liked Mrs. Brunette. She went on to explain that Mrs. Brunette was very easy to get along with and that she respected their marital privacy.

ER How about your husband?

Mrs. Brunette-D He's good. He favours her. Yah, he's very good. Never, ever raises his voice to her. She, she's not hard to get along with. She's easygoing, you know what I mean. She's not a cross person, you know. Like, she'd never meddle into our marriage. Or nothing. She's a saint.

Mrs. Brunette's daughter-in-law also talked about Mrs. Brunette's personality depicting her as a 'strong' person who had lived a hard life. She talked about how the family was trying to be strong for Mrs. Brunette. Being strong seemed to be equated with letting Mrs. Brunette know that it was okay to cry and that she did not need to be the "Rock of Gibraltar".

Mrs. Brunette-DIL She's a very, you know, uh strong lady. Um, but I think right now ah, she needs a lot of support where uh, basically I think it's companionship. And uh, trying not to uh...And uh, I think what it is, is that uh, through the support of the family, is that we're trying to be strong. And um, like we're doing what we can for her. And, like I said before, we're reassuring her that it is okay if she wants to cry, she can cry. And if she has a bad day then that's fine cause we all have bad days. She doesn't have to be the Rock of Gibraltar. And that's exactly what she's trying to be.

Properties or attributes of change for Mrs. Brunette included sadness, passive acceptance of the change, and the need to be cared for and loved. Whereas attributes for Mrs. Brunette's daughter included feeling scared to leave Mrs. Brunette alone and feeling responsible to take care of Mrs. Brunette. Mrs. Brunette's daughter-in-law and daughter both depicted Mrs. Brunette as a strong person who had led a hard life, a survivor. Mrs. Brunette's daughter-in-law thought Mrs. Brunette's daughter was unsure about a lot of things and family experts might be giving her the 'wrong' information.

Conditions that led to the change in living arrangements were the recent death of Mrs. Brunette's husband who had been her caretaker, deterioration of her health, family uncertainty concerning whether Mrs. Brunette would summon help, Mrs. Brunette's need for love, need to be taken care of, and the family need to take care of her and protect Mrs. Brunette from harm.

Consequences of the move were feelings of being stressed expressed by the daughter. There was no family conflict about the change in living arrangements.

Mr. MacKenzie and Family

Mr. MacKenzie was hospitalised in the intensive care unit when I interviewed him. He was hospitalised to adjust his medications in an attempt to ease his breathing problems. During the interview Mr. MacKenzie said that up until two months earlier he had been living alone in his own home. He reported during the interview that he had multiple health problems including a recent amputation and diabetes and was now hospitalised in the intensive care unit for treatment of his congestive heart failure. He also said that following the death of his wife several years earlier, he had struggled through a severe bout of depression that lasted for over a year. He said his daughter had been instrumental in helping him to overcome his depression.

He had recently sold his home and moved into residential independent living quarters at the insistence of his daughter who lived over 200 miles away. Both he and his son described his daughter as his main caregiver. He had not wanted to sell and leave his home.

ER Hum, when did you move into Littletown?
Mr. MacKenzie About two months ago.
ER Two months ago?
Mr. MacKenzie Yeah.
ER Out of your own home?
Mr. MacKenzie My daughter wouldn't let me stay alone.

ER Yeah.
 Mr. MacKenzie She wouldn't let me go in an apartment.
 ER She wanted you to be with people?
 Mr. MacKenzie She wanted me to be with people. She wanted me to be where there's nursing care. In fact we discussed this for about four months. Where she got mad at me. I got mad at her. I'm not going to no senior home. I'm going to an apartment. Okay, I'll agree to selling the house and go in an apartment. NO WAY, NOO WAY. No way, no way. She made me try a few homes there in her community. I didn't like the food there. She made me try this one here and oh, fine, yeah.
 ER You said yes?
 Mr. MacKenzie She says, she doesn't want to worry.

Mr. MacKenzie said that his daughter felt he should not live alone, especially after he had his leg amputated. After the amputation he had been on a waiting list for rehabilitation. His daughter was so distressed by the length of time it was taking for him to start a rehabilitation programme in his community that she arranged to have him move to her community where he immediately began a rehabilitation programme. After completing the programme, he returned to live in his own home. However, the amputation combined with his heart condition severely limited his ability to look after his home and garden. He said that he and his daughter argued for four months about the need for him to move into a protected environment where he could receive care if needed and where he would be with other people. He finally relented and decided to look at two different residential homes. One was located near his daughter's home and the other was in the community where he had always lived. He chose the latter. During my interview with him, he was indifferent about the residential home and said he had moved to please his daughter because she worried about him living alone. I did not interview Mr. MacKenzie's daughter because she lived out of town.

Properties of the change in living arrangements included Mr. MacKenzie living alone and his history of depression. His family (Mr. MacKenzie, his son and daughter) had a history of taking care of Mrs. MacKenzie during a lengthy, terminal illness that was devastating to all of them according to Mr. MacKenzie and his son.

This family demonstrated the need to protect Mr. MacKenzie, however, this did not entail incorporating him into either his son's or his daughter's households. His daughter lived several hundred miles away, worked outside the home, and had children and a husband.

Conditions that precipitated the change in living arrangements included further deterioration of health, multiple health problems including the recent amputation of his leg, and his daughter worrying about his ability (mental and physical) to manage living alone.

As a consequence of pressure from his daughter and after considerable conflict between them, Mr. MacKenzie finally sold his home and moved into residential care. He was indifferent about the move.

Mrs. Levesque and Family

Mrs. Levesque was a 59 year old woman who had her first heart attack at the age of 52. She had experienced a gradual deterioration of her health during the two years prior to her most recent hospitalisation for congestive heart failure. She had been hospitalised on an emergency basis six weeks prior to my interview with her. She had experienced extensive cardiac damage and could not climb stairs or walk a block without becoming extremely short of breath. In fact, at times during my interview with her, which occurred in her home, she had to stop talking in order to catch her breath. She became an informant in the study through the cardiac rehabilitation program.

During my interview with her she told me that she and her daughter and her daughter's partner talked about having her sell her house and move into a granny flat

in their home. This decision occurred while she was in the hospital six weeks prior to my interview with her. The decision to move was precipitated by her recent hospitalisation and her extreme difficulty breathing, a consequence of her heart disease. Her heart condition severely taxed her ability to carry out household chores such as cleaning, making the bed, and even cooking. She was very close to her only daughter and viewed the move very positively as an opportunity for them to become even closer. Also, she was worried about her daughter because she had been cleaning and looking after two households, her own and Mrs. Levesque's, while working full-time as a manager of a small business. Mrs. Levesque wanted to reduce her daughter's workload. Her daughter and her daughter's partner said that they had always planned to look after either of their mothers should the need arise.

ER Is it because of the illness right now that you've decided that your mom is gonna live with you?

Mrs. Levesque-D Well, I eventually wanted to anyway. I want to take care of her.

Mrs. Levesque It's her turn (*laughter*)

Mrs. Levesque-D So, it's just easier too. Like, I don't always get to see her all the time cause we're (*she and her partner*) always working. It's hard.

ER Well that's great that you can work this out cause.

Mrs. Levesque Oh, yeah. Cause uh, even myself uh, I worry at night, you know. I'm alone and uh, I had a little dog. But then, I couldn't pick him up, you know. He's too heavy and I couldn't wash him or anything and always go to the door to let him out. I'd get cold, you know. So, the neighbour look after Barney when I was in the hospital and then well, I had to decide to, you know, to sell the house and I wanted a good home for the dog and he's right next door. He (*the dog*) comes and see me almost every day. And he's a good dog.

Mrs. Levesque's daughter said that she wanted to "take care of Mrs. Levesque" echoing a similar sentiment expressed by Mrs. Brunette's daughter. The daughter also expressed difficulty even seeing Mrs. Levesque as much as she wanted because she and her partner were always working. If they were living in the same household she would be able to see her and take care of her every day.

Mrs. Levesque then explained that her illness prevented her from carrying out simple as well as more complex household chores. Doing even the lightest of

housework left her breathless and in pain. As well, uncertainty about the future influenced the decision to move. All these reasons were given as justification for the move to her daughter's home.

ER So, how soon is the move?
Mrs. Levesque Ooh, as soon as possible. The real estate is coming Monday. So they, they probably put the card (*for sale sign*) you know. That's the first time that somebody, that I decide, you know, to sell, because uh....I can't keep up. No
ER It's just too hard?
Mrs. Levesque Oh yes, and vacuuming, OH MY GOD!
Mrs. Levesque-D You can't do it!
Mrs. Levesque Even it's hard on her (*points to her daughter*), her back you know.
ER Yeah, yeah. You get too short of breath?
Mrs. Levesque Oh, yeah, yeah. Even when I wash the dishes. There's not much, just me. My back hurts (*when Mrs. Levesque had her first heart attack the pain she experienced was between her shoulder blades*) so much that I have to sit, I gotta sit and stairs, well, it's impossible. I don't even try!

Mrs. Levesque's daughter and her partner wanted her closer to his family as they thought she was isolated living alone on the other side of the city from where they lived. Mrs. Levesque's daughter stressed the proximity of family in the new location. Family would always be available to Mrs. Levesque whereas there was no family living close to Mrs. Levesque's current home. The daughter also said that the move would help to prevent Mrs. Levesque from becoming depressed. In the past, Mrs. Levesque had experienced depression due to being alone. This is similar to the rationale provided to justify Mr. MacKenzie's move into residential care. Mrs. Levesque corroborated feeling depressed at times and also attributed this to being alone.

Mrs. Levesque-D But there will always, usually always be somebody at our place anyway and there's family all around.
Mrs. Levesque Oh, oh yeah.
Mrs. Levesque-D Closer. Everyone, like my boyfriend's family is all around there so they just. They know my mom is moving in. So it's just a phone call away and better than down like, down at this end (*of the city*) where she's by herself.
ER Family?
Mrs. Levesque-D Yeah, yeah. And then this way she can be with us a little more, and she won't be alone, because I find when she's alone she gets depressed. And at least you're interacting with other people too.
Mrs. Levesque Like I know Mike's mom (*mother of daughter's partner*), and his sister. They got two nice little boys. And I'll be able to see them more, you know. Here they came when I was sick and I mean it wasn't a good time, you know. So uh, and the little

boy he remember at Christmas Eve I went to Madame Levesque's house and the little boy said, "Ohh, you were so sick". He said, "You're better now, eh!" He remember from seeing me sick. He said, "You're okay now."

When I asked Mrs. Levesque's daughter to explain what kind of an impact her mother's illness and the proposed move had on her, she responded by describing being scared and worrying about her mother. A sense of the need for control was evident as she talked about needing to have her mother located close to her so that she could "get to her in time". She also depicted worrying as being something that she said, "moved back and forth between herself and her mother". Again, being afraid was an experience common to other study participants (Mrs. Roy, Mrs. Pageau, Mrs. Brunette) that influenced changes in living arrangements. Moving to a location where the patient could be watched seemed to be a common solution to the problem.

ER So what kind of an impact would you say all of this has had on you?
Mrs. Levesque-D Scary. Very scary. A lot of worrying, that's why I want to get her with us. That's my biggest concern just so that then it's the less worry. If something breaks here. If she falls down here and I can't get to her in time. And this way everything, well she doesn't have to worry about it. Cause when I see her worrying then I worry and it just goes around and around.

Mrs. Levesque was happy to sell her home and move in with her daughter. Mrs. Levesque's husband had died fifteen years earlier and her daughter was her only child. During the interview their affection and concern for each other was observed by the way they touched and looked at each other. So for Mrs. Levesque, moving in with her daughter was a welcomed event. However, Mrs. Levesque did experience some significant losses with the move. She could not keep her little dog, not only because she could no longer care for him, but also because the dog was not wanted by her daughter and her daughter's partner. She loved her little dog and was sad about having to give him away. She rationalised this loss by saying she could no longer care for him, bathe him and so on. A second loss involved a friendship that she had with a

female neighbour who lived across the street whom she had known for years. She did not want the move to interfere with some aspects of her life. For example, she planned on keeping the same doctor and the same pharmacist. She had gone to the same pharmacist for many years. "Jack", as she called her pharmacist, would phone when she had a new prescription to make certain that she understood her medication.

Mrs. Levesque I've got a good pharmacist. We have him since 1973, and Jack when the doctor prescribe those (*inhalers*) he make sure I knew how to use them. And uh, like uh, sometimes, like this one, you don't inhale. I thought you could, you know. Like this you inhale and hold it as much as you can. And then you let it out. But this one you just spray it. Cause we take that only the reaction. Some people have to use that when you start having pain.

Mrs. Levesque acknowledged feeling depressed living alone and wanting to be closer to her daughter. Mrs. Levesque's daughter expressed the need to take care of and protect her mother. Her daughter's home was large enough and already had a granny flat ready and waiting for her.

The conditions that precipitated the move included her daughter's concern about Mrs. Levesque being alone, their joint acknowledgement of Mrs. Levesque being depressed, and Mrs. Levesque's deteriorating health which made basic household chores too much for her. Other conditions included the daughter's need for Mrs. Levesque to be near family and Mrs. Levesque's concern that her daughter was doing too much, working full time, and looking after two houses. Mrs. Levesque's daughter also expressed the desire to take care of her mother again. Uncertainty about the length of time left in Mrs. Levesque's life and the wish to spend more of that time together with her daughter was also a factor that influenced her decision to move in with her daughter.

For Mrs. Levesque the proposed move into her daughter's home entailed losses, however, there were also gains. Losses included loss of a beloved pet and of

a long-time neighbour and friend. The gain of being closer to her daughter outweighed the losses. The consequence of the move, from the daughter's perspective, was to protect Mrs. Levesque and to enhance an existing warm relationship.

Changes in Patient and Family Activities of Daily Living and Relationships

In addition to changes in living arrangements, patients and families also experienced changes in activities of daily living and relationships. Comparative analysis of the changes faced by patients and their families will be presented and their properties, conditions and consequences delineated. The changes in activities of daily living and relationships experienced by patients and families, specifically Mrs. Brunette, Mr. Martin, Mrs. Valenti and Mrs. Houle follow.

Mrs. Brunette and Family

When I interviewed Mrs. Brunette for the first time, she was hospitalised with congestive heart failure and was grieving over the recent death of her husband two weeks earlier. As described earlier in this chapter, after the death of her husband, Mrs. Brunette's eldest daughter and son-in-law had moved into her home to care for Mrs. Brunette. Several weeks after Mrs. Brunette had been discharged from the hospital, I interviewed Mrs. Brunette's eldest daughter in her home. I then interviewed Mrs. Brunette and eight members of her family including her eldest daughter.

During the hospital interview, Mrs. Brunette indicated that her daughter looked after her medications and during the family interview I learned that prior to his

death, her husband had looked after her medications. Changes in activities of daily living focused on Mrs. Brunette's daughter taking over responsibility for giving medications to her mother and negotiating what household chores Mrs. Brunette could do. Having the eldest daughter take responsibility for Mrs. Brunette's medication involved a change. However, the change mimicked past patterns of care familiar to Mrs. Brunette. In the past, her husband had been responsible for her medications; now her daughter had taken on that task. During the family interview Mrs. Brunette's daughter explained how she had promised her father on his deathbed that she would look after Mrs. Brunette and her medications.

Mrs. Brunette-D And he was so worried about ma because dad always took care of all the pills, eh. He was so worried about her eh, and when he died I held his hand. I didn't want him alone to die, eh. I told him eh, dad don't worry about mom. I said, we'll take care of her. We'll make sure we take care of her. Don't worry! Cause dad eh, was all worried about mom, eh. Yah.

The responsibility of this task terrified Mrs. Brunette's daughter. She was afraid of hurting her mother. As well, during the family interview it became apparent that internal conflict had arisen between family members. Mrs. Brunette's daughter had taken the advice of a family member 'expert' (a registered nurse) which led to conflict with another daughter-in-law (Mrs. Brunette-DIL). Mrs. Brunette's daughter explained the conflict that occurred between herself and Mrs. Brunette's daughter-in-law arose from her responsibility for Mrs. Brunette's medications. A second daughter-in-law interjected with "it's the stress". Mrs. Brunette's daughter's feelings of being responsible and of being afraid of hurting Mrs. Brunette came through repeatedly during the family interview. Emotional turmoil and confusion permeated this part of the interview, during which Mrs. Brunette's daughter began to cry and Mrs. Brunette's daughter-in-law said she didn't mean to hurt Mrs. Brunette's daughter.

Mrs. Brunette-DIL I didn't mean to hurt you (*Mrs. Brunette-D*).
 Mrs. Brunette-D That's the thing.
 Mrs. Brunette-DIL I didn't mean to do that. But
 Mrs. Brunette-DIL2 It's a lot of stress that's all.
 Mrs. Brunette-D It's just that these pills. I'm not saying her (*Mrs. Brunette*). They (*familyexpert*) tell me how to give her, her pills. I'm responsible for her pills, eh.
 ER Yes, yes.
 Mrs. Brunette-D Like you know, eh. I don't want to hurt her.
 Mrs. DIL2 Yeah, yeah.

Earlier during the interview Mrs. Brunette's daughter-in-law (Mrs. Brunette-DIL) suggested that there was past unresolved conflict between herself and other members in the family and that this had re-emerged since Mrs. Brunette had been hospitalised. Mrs. Brunette's daughter-in-law spontaneously began talking about this conflict during the family interview and suggested that "things have happened over the years". Mrs. Brunette's daughter-in-law then suggested that she was "just tolerated" by other members of the family. Only Mrs. Brunette and Mrs. Brunette's daughter responded to the outburst and they did so in monosyllabic agreement. Then Mrs. Brunette's daughter began to cry.

Mrs. Brunette-DIL No, but I'm just saying, like uh. Jane (*Mrs. Brunette-D*), it's not gonna change.
 Mrs. Brunette-D No.
 Mrs. Brunette-DIL Things have happened over the years. And
 Mrs. Brunette-D I know, I know.
 Mrs. Brunette-DIL And I've tried really hard to be there for all of you and no matter. When it comes to me, it seems it's just not. I'm tolerated, but not really. You know what I'm saying,? So, it's best if we just. I will always be there and I'll probably be there no matter what kind of bullshit goes on.
 Mrs. Brunette Uh, huh.
 Mrs. Brunette-DIL But, I don't know where my boundary is now. So, and as I said, it hurts and I know that at times you've been hurt too.
 Mrs. Brunette-D Yeah.
 Mrs. Brunette-DIL What can I tell you. I've heard ten stories of something that I didn't do.
 Mrs. Brunette-D Yeah.
 Mrs. Brunette-DIL That I did the best I could. You know what I'm saying mom.
 Mrs. Brunette Yeah, I know.

Later during the same family interview the topic of medication and Mrs. Brunette's daughter's feeling of being responsible and fear of hurting her mother again emerged, emphasising her confusion and uncertainty about her medications.

Mrs. Brunette attempted to pacify everyone by saying “I’m doing good” and Mrs. Brunette’s daughter-in-law offered a reassuring “she looks good”. I offered to provide her with information about the medications to which Mrs. Brunette’s daughter responded in a desperate voice, “yes, please”. She then rushed on and showed her confusion about the purpose of the various medications and did not know which medication had been discontinued. Her anxiety over her mother’s medications and the responsibility she felt for them seemed to overwhelm her. Confusion extended beyond Mrs. Brunette’s daughter to include the two other daughters-in-law who were participating in the interview, each of whom offered differing opinions about the purpose of her medications. Throughout Mrs. Brunette sat quietly, occasionally nodding her head.

Mrs. Brunette-D	It’s just that. You know, it’s just that because I’m the one that’s responsible for the pills and that...
Mrs. Brunette-DIL	That’s right.
Mrs. Brunette-D	Like I don’t want to hurt her.
Mrs. Brunette	I’m doing good.
Mrs. Brunette-DIL	She looks great .
Mrs. Brunette-D	Yeah, yeah.
ER	I’ll get you ah, ah, a proper, understandable description of each <i>(medication)</i> <i>(Mrs. Brunette-D interrupted before I could finish my sentence)</i>
Mrs. Brunette-D	Yeah, okay please.
ER	And what the side effects are—anything that you look for if she’s getting too much.
Mrs. Brunette-D	Yeah, yeah. Like, he cut off the yellow pill. What was that? The blood pressure pill?
Mrs. Brunette-DIL	The water pill.
Mrs. Brunette-DIL2	No, it was the water pill, eh.
Mrs. Brunette-D	No, the water pill is the little white one.
Mrs. Brunette-DIL	Is it?

In contrast, Mrs. Brunette spoke of her medications in a matter of fact voice when she told me that her daughter looked after them as indicated in the following excerpt.

ER	Do you have a way of looking after taking medications?
Mrs. Brunette	Yeah, we <i>(she and her daughter)</i> have a little red box, and it’s Monday, Tuesday all week.
ER	And so its all set up for the week?
Mrs. Brunette	Yeah, and my daughter fix every week. On Saturday she fix all the medication.

ER Uh, huh.
Mrs. Brunette Yeah.

The topic of medications re-emerged frequently during both individual and family interviews and was reflective of the degree of anxiety experienced by Mrs. Brunette's daughter over this new task. Mrs. Brunette's daughter's sense of responsibility and anxiety came out during the family interview when she provided an unsolicited, detailed explanation of how she intended to manage her mother's medication regimen so that they could attend a family wedding. She didn't know what some medications were for, she was terribly concerned about not missing a dosage and about making certain that Mrs. Brunette would get her medication on time. As she talked about being responsible for her mother's medications she became quite agitated, her voice rose, and she was wringing her hands. Both verbally and non-verbally she indicated how stressful she found responsibility for this new task to be.

Mrs. Brunette-D Now she's only on one patch a day eh, that was cut down. And her medicines, some of her medicines, okay, I don't know what they are. (*highly anxious, wringing her hands*) They're little yellow pills that was taken away, like for her special technique. She was all right. Course they (*the nurses*) never told me anything. It was the doctor who told me how to give her, her pills eh.

ER Um hum.

Mrs. Brunette-D Be sure the valid time and everything. Like you know, you know, we're going to a wedding on Saturday. So the supper's only at 6:30 (*pm*). So, I told my sister, I said, well, I've gotta give her, her pill at five (*pm*). So, she's gonna have kind a like a buffet or something. So, I give her, her pill at five (*pm*) cause that's about an hour and a half late eh at 6:30 (*pm*). And I want to give it to her on time, eh.

During the family interview, when I asked the family in general about the impact Mrs. Brunette's illness had on the family, Mrs. Brunette's daughter responded first. She stated in a forthright manner that they were all afraid that Mrs. Brunette was going to die. The eight other family members who were sitting around the kitchen table nodded their heads in agreement. Mrs. Brunette sat quietly while her daughter voiced her fears aloud.

ER What kind of an impact do you think her illness has had on the rest of you, on the family?

Mrs. Brunette-D Well, well we're all scared she's gonna die, eh. I've been living with that. None of us, you know, we love her dearly, you know, the whole family. Well, like one day, we'll lose her, you know. But, I don't know how I'm gonna deal with that part though.

During my interview with Mrs. Brunette's daughter she also talked about other changes that had happened since her mother had been hospitalised with congestive heart failure. She said that she did everything for her mother. However, she also stated that she couldn't take everything that her mother liked to do away from her.

Mrs. Brunette-D And uh, so I do all of her. I do everything, everything. The only thing that she does is a little bit of supper and she likes cooking so much. So, I can't take that away. She's gotta do a few things, you know, like that, eh. She helps with the dishes, you know.

Later during the same interview she indicated that she was concerned about her mother's strength because she tired easily. She talked about having to negotiate with Mrs. Brunette about what she should and shouldn't do. She alluded to her mother's wish to try to do things that she thought her mother should not do but at the same time she recognised her mother's need to do things.

Mrs. Brunette-D She's not as strong as she was. She gets tired easy. Like I, that's understandable, you know. Cause I had noticed a big change in her. Cause my mother's a strong person, you know. Yah, but there's still lots to negotiate. Well, I'll try it. But, I think she shouldn't 'cause it's too much for her.

ER Yeah.

Mrs. Brunette-D Yeah, you know. It takes a lot of time you know, cause you know it's still hers.

Properties of the change included personality characteristics of Mrs. Brunette who passively accepted her daughter assuming responsibility for her medication. Mrs. Brunette had not changed her pattern of living. Her daughter assumed Mrs. Brunette's husband's responsibility for Mrs. Brunette's medications. Properties of change for Mrs. Brunette's daughter included recognition of the need to negotiate household tasks with her mother, fear of hurting her mother, feeling overwhelmingly

responsible for her mother's medication, and taking care of her. She was uncertain not only about what medications her mother was taking but also about their purpose. She also feared that her mother would die and was uncertain about how she would deal with that event. The family exhibited confusion about the purpose of medications and a past history of unresolved family conflict emerged during the family interview.

Conditions that precipitated changes included the recent death of Mrs. Brunette's husband, the sudden, unexpected deterioration of her health, and a promise to Mrs. Brunette's dying husband made by his daughter (Mrs. Brunette-D) that she would take care of Mrs. Brunette. Consequences of the change in responsibility for Mrs. Brunette's medications included Mrs. Brunette resuming an established pattern of being taken care of, her daughter and family needing information, and the family experiencing conflict.

Mr. Martin and Family

Mr. Martin had experienced his first heart attack in 1989 at which time the doctors had told his family he was unlikely to survive. Since that first hospitalisation he had been repeatedly admitted to the hospital for the treatment of congestive heart failure. He reported five hospitalisations during the past year alone. Subsequent to his heart disease he developed diabetes and last year he was diagnosed with prostate cancer. A year prior to my interview with him, a surgical procedure for prostate cancer had to be terminated before it was completed because he had a heart attack on the operating table. He took multiple medications for his heart condition and was taking insulin and antineoplastic medications. At the time of my interview with him he had been hospitalised to adjust his heart failure medication and for home oxygen

assessment. He had extreme difficulty breathing to the extent that he could not sleep at night. He also had grossly oedematous extremities which caused him pain and which had interfered with his ability to walk around his house. He had some difficulty getting up and down the short flight of stairs from the living room area to his bedroom.

For Mr. Martin, role changes had happened following his heart attack in 1989.

At that time he was forced to go on disability pension because of the extent of damage done to his heart. When asked what kind of impact his illness had on his family, he responded by describing tasks that he could no longer do and indicated how he had handled not being able to do household tasks. He spoke of his son with a great deal of pride and affection. He said his family had accepted that he could no longer do what he had been able to do prior to his heart attack.

ER What kind of an impact has it had on your family?

Mr. Martin Uhm. Well, it's uh, they've accepted it. Uh, I can't do the things I used to do, uh like cutting my grass and everything like that. Uh, my son just volunteers and pitches in and does all that for me. And so, when I was building a deck out the side of the house, I couldn't do any actual work on it, uh, but I designed it. So, I supervised it. He did the work.

I then asked how he thought his wife had handled his illness. As he had in the discussion about his son, he talked primarily in both cases about physical tasks and chores and described how she did everything herself now. He said that it had been a slow adjustment letting her do things that in the past he had done. He talked about having a "personal guilt" at not being able to do these things and that even now he would try and then realize he just could not physically do them. His last statement was telling because he said he "did not know what her reactions are".

ER How about your wife?

Mr. Martin Oh she's very, she's a queen, yeah. She's very helpful. She won't let me lift anything, do anything. She does it all herself. I wouldn't let her when I was in shape. I wouldn't let her do any manual type things. But uh, now she does it all herself. She carries her own suitcase and puts her own golf clubs in the car, which I always used to do. But uh, oh well.

ER Has that been okay adjusting to that?
 Mr. Martin Oh, yeah, uh huh it's a slow adjustment. It's a slow adjustment. But sometimes, I get, uh oh a you might say, a personal guilt. But uh, why can't I do that--then I try it and oh.
 ER And you know you can't?
 Mr. Martin Then I know I can't, yeah, yeah.
 ER Sort of recognizing the physical limitations?
 Mr. Martin Yeah.
 Mr. Martin Now, what her reactions are I don't know.

I interviewed his wife in their home while he was still hospitalised. Unlike him she did not talk about any of the changes that he had talked about. She spoke in more general terms about how they were both very independent people and always had been and suggested that had not changed. She said that she had never depended on him nor he on her. The following quote illustrates her view of their roles.

Mrs. Martin Yeah. Oh we've always been pretty independent. I've never depended on him and he's never depended on me, really (*laughs*). We've always done our own thing.

Mrs. Martin initiated her interview with the following statement which reflected her thoughts about her husband's current health status. Her words revealed that she did not believe that he had long to live. Furthermore, she did not believe that her husband was aware of how close the "end" was. She indicated that the doctor had not given them much "hope". She repeated that she didn't know how much he knew and that they did not talk about it.

Mrs. Martin And well, of course, there's, I know from past experience with my mother and all that. I know that when their feet swell up like that its sort of towards the end.
 Mrs. Martin I don't think that he realizes this. Of course, the doctor hasn't given us very, given us very much hope either.
 ER Um hum.
 Mrs. Martin I don't know how much he knows and I don't say anything.

Later during the interview Mrs. Martin again referred to not having been given much "hope" and she again said that her husband didn't talk about it and never had. He had never talked seriously about death and had always said "everything's fine"

even before he became ill. Mrs. Martin was distressed and crying when she talked of Mr. Martin being close to the “end”.

- ER You were saying that the doctor had said that this is really, really serious.
Mrs. Martin He's told me that before, he told me that a year ago. I mean, you know, he has never given me any hope almost right from the beginning, that uh (*long pause*).
ER How did, how do you think your husband perceives all of this?
Mrs. Martin Well, I don't know whether he realizes about this last bit, that eh, the fact that the swelling in his feet means that he's not eliminating the water. I'm sure he knows that. So, I don't really know. He doesn't really talk about it you know. He doesn't really say too much.
ER Do you think there are things he needs to sort out... or, I can sense you're worrying?
Mrs. Martin Yeah.
ER He doesn't really want to talk about it?
Mrs. Martin NO! (*emphasised*) but he never has. He has never been one to talk seriously about anything. No, always, everything's fine.
ER Yeah, he likes to be in control? He likes to tell you how?
Mrs. Martin Yeah, exactly .

Mr. Martin had always taken full responsibility for his medications. Mrs.

Martin had limited knowledge of what his medications were or when he took them.

- Mrs. Martin Cause I'm not even sure of all the medications. He knows everything he takes and there was this one I don't know which one. The cancer pill he still takes the cancer pill, as far as I know. He takes a shot, I know that. That's once a month. And that he was taking another pill I think.
ER But he manages it all himself?
Mrs. Martin Oh yeah, yeah he looks after everything, besides that I don't even know for sure, I mean, I know the names just because he tells me.

Mr. Martin's son expressed views similar to his mother saying that he really didn't think anything had changed all that much. He said, “He's just away. He was always away when we (he and his sister) were growing up.” As illustrated in the following excerpt, Mr. Martin's son focused on their relationship when I asked if there had been any changes in the family since Mr. Martin had become ill.

- Mr. Martin-S I guess..... from my perspective he was never around when we were growing up anyway, so it's no different. He was a travelling salesman. We didn't see him that often. So, it was.....there's really no change in the relationship. That's the relationship we've always known him by. He's just not there. He's travelling.

Mr. Martin's son described his father as being “very stubborn. I guess that's what helps him get through it, stubborn as a mule”. He went on to say that he didn't

think his father had thought of himself as ill until just recently. Mr. Martin's son felt his father had just started to "recognise that it's a major limitation. It's scary." He talked about his father's illness as being a consequence of "the life he led" implying that his illness was his own fault. During the next part of the interview he became quite emotional and had tears in his eyes as he said, "It's sad, I've got to take this gradually. His grandchildren won't know him". During the interview I asked what impact his father's illness had on the family and from his son's perspective, his father's illness didn't "stop or really interfere with anything". Mr. Martin's son stated that "to somewhat extent we've somewhat ignored it." Unless his father was hospitalised, life went on as usual "just the normal family interaction for whatever reason". He felt the greatest effect of his father's illness was on his mother "because she's there with him every day. Whereas my sister and I are on our own so that we don't, we're not exposed". He described his father's illness as having many bouts or relapses and included several episodes over the years where the family had been told that "he had only a couple of days, back in '89" or "he's a very sick man" or "he had two years". Mr. Martin and his family have lived with the uncertainty of his death since 1989. However, Mr. Martin's son thought that this current episode of illness was "one of the worst" and felt that his father "hasn't bounced back as well as he normally does".

Properties that affected Mr. Martin's activities of daily family living and relationships included his independent, optimistic, and stubborn personality. Family interactions that included Mr. Martin were characterised by ignoring his illness and possible death. However, interactions that occurred between Mrs. Martin and her son and daughter included this eventuality. The family also expressed a feeling of sadness because Mr. Martin would not know his grandchildren. There were differing opinions

about changes in daily family activities. Mr. Martin's son said there were no changes in activities of family living or relationships because his father was always away when he and his sister were growing up. On the other hand, Mr. Martin felt that there had been many changes in activities of daily living and he felt guilty about them.

Conditions of change for family activities of daily living and relationships for this family included the deterioration of Mr. Martin's health status—his extremities were chronically edematous and he was extremely short of breath to the extent that he required home oxygen. Mr. Martin's son said that he and his sister felt Mr. Martin's illness was his own fault because of his lifestyle as a travelling salesman.

Consequences of the changes in his health status on family activities and relationships included differences in perceptions between family members. Differences included Mrs. Martin's interpretation of Mr. Martin's peripheral oedema as being a sign of his imminent death—an issue never discussed by Mr. Martin. Mr. Martin now saw himself as planning activities while his family carried out those plans. However, his family did not acknowledge this change. It appeared that responsibility for Mr. Martin's health regimen continued to rest solely with him.

Mrs. Valenti and Family

Mrs. Valenti was a 64 year old woman who experienced her first heart attack in 1982. She had multiple coronary bypass graft surgery in 1985. Her husband was told at that time that the surgery was unsuccessful. During the year following her surgery she was extremely ill and spent the majority of her time in bed. According to both Mrs. Valenti and her husband after a long period of trying to adjust medications, the cardiologist finally found the right combination of drugs to bring her congestive

heart failure under control. During the interview with Mr. Valenti, he said that the cardiologist had told him that only one third of her heart was functioning. She and her family became study participants through the cardiac rehabilitation program.

During the interview with Mrs. Valenti which took place in her home, I asked if she had experienced any changes since she had been ill. She responded quite fiercely that she did all her own housework. She indicated that her husband wanted to hire a woman to do the cleaning. Her tone of voice and her words, "If I can't do it, then I don't want to be here" indicated just how important and central household tasks were to her. I observed that her house was neat and extremely clean. She did say that she got tired at times but that she wasn't one to sit about watching television. She seemed to equate doing with being alive and said that if she couldn't do her housework then she did not want to be around.

ER Do you think it's changed any of the roles? Inside you know, who does what inside the family, since you've been ill or do you still do the same?

Mrs. Valenti No, I do all my own. I do all my own things in the house. He wants me to bring somebody in to clean. But I refuse to have anybody in to clean my house. As long as I can do it. You know, if I can't do it. If I can't do it then I don't want to be around so. You know (*the house was immaculate*).

ER Yeah, so how do you work that out though? Because you like a tidy clean house, I can tell.

Mrs. Valenti I, I just do it. You know, sometimes I don't feel. I get tired, very tired sometimes, but uh, I feel. He'll tell you. I don't sit down and watch TV. You know, I listen. I have the TV on there, listening to folks. I'm in cooking or I'm doing my ironing or whatever. But uh, I don't sit and watch TV.

Both Mr. and Mrs. Valenti were well aware of the seriousness of her heart condition. They both talked about the possibility of her death. He was very aware of the amount of damage that had been done to her heart. He saw his role as "keeping her going in the right direction" and "letting her do things" while at the same time trying to keep her from doing too much. He was protective but also trying to balance what she did. This man sold his business and retired from work after his wife's

surgery. His business required long trips away from home and he no longer felt that it was feasible to be away from her.

- Mr. Valenti Oh, by the way, I never stopped her from working. No, I just sit back. Sometimes, I give her heck over it, but I don't stop her. No, I never stop her. I give her heck afterwards but meanwhile let her do it.
- Mr. Valenti Yeah, yeah. I thought my role would be really not stopping, but make sure she goes in the right direction and sort of hold her back if I can. Because she is a very determined, high strung individual. Of course I'm the same way but in a more subtle way. (*Laughs*) I get
- ER Yes
- Mr. Valenti So that, that's I thought would be my role. And it seems to work.

Mrs. Valenti's daughter described in detail the changes that had happened over the past 12 years since her mother's cardiac surgery. She painted a picture of her mother as a busy, determined woman who was a positive thinker and who had to struggle to learn to slow down because of her damaged heart. The following excerpt illustrates the many changes in activities and responsibilities that Mrs. Valenti's daughter felt had happened since her mother had become ill.

- ER Okay, would you say that there were any changes in sort of responsibilities or roles inside the family?
- Mrs. Valenti-D Yeah, because before she used to worry about everything, and you know the house had to be tidied, and everything vacuumed and stuff. But she slowed down, you know, cause Dr A told her don't worry about anybody else, don't worry about what the house looks like, you know. Worry about yourself. It took her a long time to do that. Cause she was so on the go, go. Well, she's still on the go but she knows when to slow down, you know. Now I find just in the past few years now, she says, look it's okay, I'm gonna sit on the couch. I'm not gonna worry about anything. If somebody walks in and the house is dirty, you know, I'm not gonna care. Which took her a long time for her to do. So that changed, eh, in her and her eating habits have changed incredibly. She feels whatever she can do to help herself she will do that. She quit smoking and now she's in the exercise program. But, she always was moving, she'd go for a walk or go downtown, or go to the mall. And go on the treadmill, or whatever. She's always, not a lazy person, you know. And that's a problem. Sometimes it's hard to slow her down because, you know, she's so used to going, and she doesn't want to stop, and when she's got a pain like... there's some days when she's uh, if she's not feeling well, if she watches (*what she does*) and takes the day off, and lays down, and just whatever. When the days are not sunlight and her arthritis kicks in, she won't uh. A lot of people would just say, uh, I'm in pain, you know. Just moan and groan all day. But she's not, she's not like that. She'll just keep going and say, well, you know I still have to live and the pain is there. But if I don't think about it then it'll go away, you know.
- ER Thinks positive eh?
- Mrs. Valenti-D Yes, very positive. And that's what she says, positive thinking just gets you going, you know. And that's a big thing.

When asked about the impact of her mother's illness on her father she talked about increased responsibilities that he had taken on. The example she gave focused on his role in keeping her from "worrying". She said her parents were even closer than they had been prior to her illness and depicted them as being "bonded together". She concurred with her father's statement that Mrs. Valenti came first, work second. She ended by saying "you never know what can happen".

ER What kind of an impact do you think it's had on your dad?
Mrs. Valenti-D On my dad. Oh, he's ah, he's taken on responsibility. Yeah. He's, he's um. Like he was always, uh, around for her and stuff. But now he's starting to take responsibility and do things and tell her not to worry about stuff, Um, he's, he's even cut down smoking himself, you know. It's hard for him to quit, totally. I'm not too sure exactly how much it impacted on him. But they're very close. Like if there's any problems, you know, uh, work comes second, you know. My mother's first. And uh, that's it. If there's a problem, forget about everything else. Just focus on her. So, it's more, now, you're close, you know. You really bond together. Get really closer. You never know, you know, what can happen. So, that's what I think.

Properties that affected changes in activities of daily living and relationships included Mrs. Valenti's personal characteristic of determination. Mr. Valenti depicted himself almost like a manager, setting limits, not stopping her from doing things but trying to realistically help her to do what she wanted to do. He monitored and set limits on her activities. Mrs. Valenti's daughter depicted her mother as a positive thinker who was always on the go and who had to learn to slow down. She said her father had taken on a lot of responsibility and that her parents had always been close but that now they were even closer. There was a sense of commitment and closeness among family members.

Conditions of change revolved around the limitations imposed by the health status of Mrs. Valenti's heart which led her to be tired and uncertainty about what the future might hold. Consequences for Mrs. Valenti included trying to keep her household activities the way they were prior to her illness. For Mr. Valenti

consequences included taking early retirement from his work and creating a protective environment to support Mrs. Valenti's 'determination' to do activities that she had done prior to her illness.

Mrs. Houle and Family

I interviewed Mrs. Houle, her daughter-in-law, and her husband at her home six weeks after she had been hospitalised with a heart attack. She had been identified as a study participant by nurses at the cardiac rehabilitation program because she was taking medications used to treat congestive heart failure. She was still adjusting to the fact that she had suffered a heart attack and was unaware that she also had congestive heart failure. She had continued to experience chest pain after being discharged from the hospital. She had withheld this information from her husband initially because she did not want to worry him. She was uncertain about when things were going to get back to the way they were prior to the onset of her illness and really thought surgery was the only answer for her.

Mr. and Mrs. Houle lived in low-cost housing and were barely able to manage financially on Mr. Houle's disability pension. Mr. Houle was ill with chronic fatigue syndrome and had been unemployed for several years. Mrs. Houle had supplemented his pension by babysitting their grandson. Since the onset of her illness she was no longer able to babysit which was a financial and an emotional loss for her.

The family interview consisted of Mr. and Mrs. Houle only because Mr. Houle did not feel his sons and their wives were responsible for looking after Mrs. Houle. He felt responsible for Mrs. Houle's care and he did not want his children interfering. He thought too many people telling her what to do would be confusing for her.

Mrs. Houle's daughter-in-law portrayed Mrs. Houle's illness as really upsetting because Mrs. Houle was their babysitter. However, concern for Mrs. Houle's health seemed to outweigh babysitting needs. Mrs. Houle's daughter-in-law and grandson were visiting when I interviewed Mrs. Houle. There was obvious affection between the grandson, daughter-in-law, and Mrs. Houle as evidenced by the way everything stopped when the child entered the room and the warm looks that passed between them. When her little grandson came into the room, all of Mrs. Houle's attention was immediately focused on him. Mrs. Houle's daughter-in-law suggested that Mrs. Houle was worried about getting back to looking after her grandson.

Mrs. Houle-DIL I never really um, cause I was, cause it's his mom . So, I was, you go *(to the hospital to visit)* I'll stay home with the baby. You know, and yeah. So, it um. It was really upsetting cause she was our babysitter too. So, that was very difficult for us. But, you know, she was saying, I'll be back to do everything. Noooo you get better first. Don't you worry about us.

ER Um hum.

Mrs. Houle-DIL She always was worried about coming back to work.

When asked about the impact of Mrs. Houle's illness on the family, this daughter-in-law responded by talking about the family emotional response. The family was worried, glad that Mrs. Houle had survived, and expressed a protective need to limit Mrs. Houle's activities. She also talked about not blaming Mrs. Houle for not being able to babysit. This was a loss for both the daughter-in-law and Mrs. Houle. The following excerpt highlights these reactions.

ER Um hum, um hum. So what kind of an impact would you say it had on you and on your family as a whole? On this family here and then maybe on your own?

Mrs. Houle-DIL Well, everybody is worried about her. Pretty, you know everybody is heart attack wow, you know. Like a big *(nervous laugh)*. So everybody took it pretty hard I think. Like you know, we're all don't do this and don't do that. Oh, I'll do that for you. You know and stuff like that.

ER Um hum.

Mrs. Houle-DIL And with us well, only because she was our babysitter. That was really a real you know. We don't blame her or anything.

ER Yeah.

Mrs. Houle-DIL In that way, it had a real effect. But uh, you know we were scared for her too. Christmas came and we like were all sittin' there doin' the dishes and so glad that she's still here.

During the interview with Mr. Houle he talked about the time he spent and the monetary cost of shopping for special food to meet Mrs. Houle's needs. He also indicated that he was responsible for keeping track of her medications and getting them from the pharmacy. He gave detailed examples of how he went out of his way to be helpful to her. He worried that her 'pump' would run out and so suggested that she keep track of how often she used it and suggested that she get an extra pump just in case. These were all protective, vigilant types of behaviours. He felt responsible for making sure she was okay with the ultimate goal of a faster recovery.

Mr. Houle Like it takes me. I go into the store and it takes me, maybe uh, three times the amount of time to buy four or five things for her, uh. Because you've gotta read everything that's on the label because she's a diabetic also. I've got a complete list of prescriptions. And I take care of handling them. Like she, she straightens them all out. But I make sure that all her prescriptions are there and I ask her this. Everything is lined up. She gets everything she needs and this time here, I said, well, you've been using that pump. Well, she hadn't been telling me. And I says, they say it's good for maybe a hundred fifty or two hundred shots. But if you don't realize how many you've had. So, I says listen lets put a pump in there because otherwise you may just run out and you're gonna need that extra, that extra third squirt and you won't have it. So, I, I got another pump and so, as far as her medication, goes I've got a complete list of hers because of I've got a list of my own.

Mr. Houle's annoyance with his sons came through somewhat when he said, "they're not responsible for watching what she eats, or helping her if she doesn't want to". His voice was angry as he spoke of his sons. When his wife was hospitalised one of their sons phoned the consultant's office and then went in to see this doctor for information about his mother's illness. Mr. Houle was furious about his son's behaviour because he saw talking to the doctor as his responsibility. He was also angry because the doctor told his son more than he had told him.

Mr. Houle They're (*his three sons*) not the ones that are you know, responsible for uh, for watching what what she eats, or or helping her if she doesn't want to eat what you give her. Well I can't help that. I can't twist her arm. What I try to do and you can ask her. She's on the other side now. I keep asking her constantly do you have

pain? What would you like to eat? Tell me! The thing is uh, like for us, it's a little more difficult because most of the stuff that you buy is uh, its more expensive. And uh, the disability that I get, is a thousand and twenty (*dollars*) a month. So that's very little, like, you know. We just make ends meet at regular times, so, I mean but. Ah, never mind that, you know. We'll like uh, I, I bought her some special margarine there, you know, it's two dollars more a pound than, than, than.....

ER Than the regular stuff?

Mr. Houle Than the regular stuff.

ER Yeah.

Mr. Houle But it's got no salt and it's, it's uh. And then, ah, I, I get her chicken uh, chicken breasts. Try and get her ah, like I got her, I, I got her. I talked to the, the, you know the butcher and told him, I says, I want as lean a roast as you can get me. Just a small one, and he cut it for me. Uh, I'm telling you there's no fat in there and so that it would give her something different. I tried to have something different for her.

Mr. Houle went on to say that he saw himself has her main caregiver. Not just shopping and getting her prescriptions but also trying to protect her from harmful or stressful things. He gave specific examples of how he had helped her to eat. He then said that if too many people are involved telling her things then the result would be confusion. He did not want other family members involved in her care. He was there and he did what needed to be done. The only external help that he thought they needed was from health care professionals. The following excerpt highlights these points.

ER Do you see yourself as the main caregiver?

Mr. Houle Oh, well definitely. I, I have to see myself as that because that's who I am. Like, there's nobody else. That's uh, that's uh, you know that'll prepare meals for her, or shop, or, or like I even try to stop everything that's uh, that's uh that could be harmful for her or stressful or anything. And her prescriptions, I'll order them you know and uh, and I'll ask, I keep asking her would she like uh, would she like to try something different to eat. And you know, like we've gone through, she doesn't like fish. And I got her to eat. I got her to eat fish a couple of times. And she, she enjoyed it. Uh, uh so you know, together its like having children, you can't uh. And besides that if you have too many people that are saying one thing and the others say oh, he's gonna say the same thing, you know. All you're gonna have is confusion. I think it's uh, it's probably best if uh, it is this way between her and I. And uh, of course, we need help with the medical profession, you know. Uh, like the dieticians will give us diabetes and so on and uh, and with that well, hopefully, you know that this gets a faster recovery.

During my interview with Mrs. Houle she talked mostly about her grandson and not being able to look after him—not even being able to pick him up. She could

not pick him up because she was getting chest pain just leaning over, never mind picking him up. But as well, her family, her daughter-in-law, and her husband would come as soon as they saw Mrs. Houle and her grandson both in the kitchen and would stop her from lifting him or from lifting anything. She saw her family as being very worried about her and very protective of her. They kept her from doing things that she and they had been told by the doctor not to do.

- ER How would you say that your illness has affected your family?
Mrs. Houle Um, well they're always worried you know. Like uh, like they don't want me to do nothing. Like my husband, even when the baby (*15 month old grandson*) comes over eh, it's hard. Well they told me not to lift anything, or that. A few time I sneak, you know in the kitchen, eh, I uh, picked him up. It's hard, you know. But most of the time when we see him they'll pick him yeah, because they come. Like, especially if I go in the kitchen eh, he wants, he wants up eh. He knows, well I give him. So at first, I didn't because like I said, I'd get chest pains just looking down. But sometimes, there, two three times, I picked him up, not so long, you know. And uh, oh my, my family well, they're, they're really good for me. And uh, they watch me really. They don't want me to do nothing, and uh, like uh, the...
ER To hurt you?
Mrs. Houle Yeah, yeah.
ER Yeah, so they're very protective.
Mrs. Houle Oh, yeah, yeah.
ER How do you feel about that?
Mrs. Houle Well, eh, it makes me feel good that uh, you know. But when I came out, before I came out of the hospital, the doctor told them, he told everybody uh, you know.

For Mrs. Houle her faith in God sustained her. I did not ask her if she was worried or afraid—she spontaneously told me that she was not worried or afraid. She was not afraid to go to bed at night because she had prayed to God and she believed very strongly that she would be able to handle it if she woke up at night with another heart attack. She said she knew what to do if that happened. On the other hand she could not tolerate not being able to care for her grandson. She saw surgery as a way of fixing her heart so that she could return to doing what she had been able to do prior to her illness. She did not think that her medications were working and she wanted to have surgery now.

- Mrs. Houle So, um but, like I say I'm not worried. I'm not scared, you know. I go to bed at night that sometimes I find that so surprising, you know. Because lots of people

they, when they have a heart attack, they go to bed at night and they were afraid that they would take another one. And I, really I'm, it's true like, I pray and I believe and I go to bed. I'm not afraid. If I wake up and I have one well, there is the telephone and away we go. Like uh, I'm thankful that I feel like that. That I'm not, I'm not scared, or uh, just that if I'm, if they're gonna, if this would work (*taking the medication as opposed to surgery*) good sign, you know. But it's uh, if I have to stay like that for months, and months, and months that I can't even pick up my grandson, or uh anything. That's the part I find very hard, you know. That uh, I can't lift him, lift anything. I can't put up with it and if they're gonna operate I wish they would do it now.

Personal characteristics of Mrs. Houle that affected her response to illness included her sense of spirituality. She was very calm, said she was not scared or worried, and that she had faith in God. She presented a picture of loss in relation to not being able to babysit her grandson since becoming ill. She was very impatient to have cardiac surgery done now. Mr. Houle provided detailed descriptions of how he was helping and protecting his wife from stress. He felt strongly that too many people telling her what to do was confusing. Mrs. Houle's daughter-in-law was "scared for her" and said the family was "worried about her". For Mrs. Houle's daughter-in-law, Mrs. Houle's illness meant the loss of a beloved babysitter.

Conditions of change included the ongoing cardiac pain experienced by Mrs. Houle and uncertainty about when and if surgery would occur. She did not tell her husband about several episodes of cardiac pain because she did not want to worry him. Mr. Houle was on a disability pension for chronic stress syndrome. Mrs. Houle's income from babysitting was needed to maintain financial stability.

There were many consequences for this patient and family. For Mrs. Houle her illness had resulted in the loss of her role as a babysitter. This loss had financial and emotional implications for Mrs. Houle and her family. She described her family as being watchful and not wanting her to do anything, both of which are protective behaviours. She wanted to be able to do what she had done prior to her illness. Her

husband took on more household chores and also engaged in protective behaviours of watching her activity, and monitoring her pain, her prescriptions, her food, and stress. He saw these activities as leading to “a faster recovery”. There was conflict in the family between the father and his sons and this was reflected in his refusal to allow them involved in the family interview. Overall the family was very protective of Mrs. Houle.

Summary

The substantive categories of changes in living arrangements and changes in activities of daily living, and relationships evolved as subcategories of a conceptual category that I have named family responsibility. Properties, conditions and consequences of the subcategories of changes in living arrangements and changes in activities of daily living and relationships emerged from the data.

Properties of family responsibility (making changes in living arrangements, activities of daily living and relationships) included a wide range of patient characteristics such as depression, strength, sadness, determination, fatalism, need for emotional comfort and physical support, resistance to making changes, fear of loss of independence, fear of ruining existing relationships, and wanting to maintain previous patterns of living. Characteristics of the family included the need to protect the patient, the need to take care of the patient, cohesiveness of the family, developmental needs of the family; and environmental factors such as the availability of someone or someplace to monitor the patient, house size, and distance family members lived from the patient. The Martin family represented an atypical case in the sense that Mr. Martin had a very independent personality and assumed full responsibility for his medical requirements. Although they were concerned about him, his family did not

demonstrate a sense of responsibility to take care of him despite his deteriorating health.

Conditions that precipitated family responsibility expressed through the need for changes in living arrangements included deterioration in the patients' health status and recent death of a spouse. For family members (predominantly daughters) feeling uncertain about what might happen if the patient were left alone, feeling responsible for taking care of the patient, and wanting to look after the patient either themselves or in an environment (nursing home) where they would not be alone. Recognition of the inability of the patient to carry out daily household tasks and acquiescence to a family member's wishes precipitated moves for patients. Uncertainty about whether or not the patient would call for help and subsequent fear of what would happen, worrying, and the need to monitor or watch the patient were conditions that precipitated changes in living arrangements, activities of daily living, and relationships from the perspective of family members.

Patients predominantly sought to maintain previous living arrangements and activities that existed prior to the illness crisis or sought emotional support of being closer to family. Some patients acknowledged that they could no longer carry out household chores because they were too tired and or short of breath. Family members worried about taking too much away from the patient while at the same time expressed the need to watch the patient to keep him or her from doing activities prohibited by the doctor. Other family members made changes in their own lives such as taking early retirement and organised the environment to help the patient meet goals.

Changes in living arrangements, activities and relationships were primarily associated with protective behaviours exhibited by family members who sought to protect the patient from harm either by moving in with the patient, moving the patient to the family residence, or moving the patient to a safe environment (nursing home, residential home). Families also made moves to strengthen existing close relationships or to resume habitual patterns of behaviour (taking care of the patient, feeling responsible). Patients experienced losses (loss of a home, of pets, of friends, of independence) and gains (not being alone, warding off depression, being with family) associated with moving. Other consequences included conflict between family members and between family members and the patient, and emotional reactions such as being upset.

Analysis of the interactions between patients and family members concerning changes in living arrangements and changes in activities of daily living and relationships revealed an overwhelming sense of family responsibility. An exception occurred in the case of the Martin family where the family did not seem to feel responsible for protecting or caring for him. Perhaps this could be explained by Mr. Martin's independent personality, a trait the family seemed to have always accepted, and the family's tendency to blame Mr. Martin's ill health on his former lifestyle. Family responsibility was characterised by the need to take care of the patient and protect the patient from harm. Family responsibility arose under conditions of uncertainty and further deterioration of the patient's health. The patient's illness not only affected the ill individual but also resonated through the family illustrating the impact of the ill family member on the family and the impact of the family on the ill family member. The consequences of family responsibility encompassed social,

emotional, and physical changes in family life. Social changes for families included alterations in relationships within and outside of the family, emotional changes involved increased family closeness and/or family conflict while physical changes revolved around changes in living arrangements, activities of daily living, and household chores.

CHAPTER 8

SUPPORTIVE NURSING CARE

Patients, two family members, family units, and nurses were asked to describe what supportive nursing care meant to them. For full descriptions of each family unit, see Chapter 5, Family Profiles. Nurse profiles can be found in Table 2, Appendix A.

I introduced patient, family member, family unit, and nurse interviews by saying, “While we are talking I’d like you to think about what supportive nursing care means to you”. I did this to give study informants time to reflect on what they wanted to recount about supportive nursing care. In addition, the consents and explanations of the study both described the study as being about supportive nursing care. Later during the interviews I asked study informants to describe what supportive nursing care was for the patient and for them. I asked them to give examples of what the nurse had said or done to be supportive.

In this chapter, comparative analysis of the data from the interviews with four patients who identified a particular nurse as giving supportive nursing care, their family members and the identified nurses was central to the development of the definition of supportive nursing care. Seven patients were not able to identify a particular nurse, however, they were able to give accounts of supportive and non-supportive nursing care so that comparative analysis of these interview data were integrated to illuminate differences and similarities in supportive nursing care.

Reasons given by patients and family members for not being able to identify a

supportive nurse were being unable to single out a particular nurse because all the nurses were “good” and being unable to remember the nurse’s name. Three patients and their family members could not identify a nurse who was supportive and instead gave accounts of nurses who they felt were not supportive in order to highlight what they thought being supportive meant. Even patients and family members who were able to identify a supportive nurse related both positive and negative accounts. Negative accounts were included here in this chapter because by implication they help to explain supportive nursing care. However, such accounts do not constitute supportive nursing care but rather the reverse.

Categories were developed from the interview data, links between these categories were identified, and their subcategories delineated by asking the following questions of the data:

- 1) What did patients, families and nurses think supportive nursing care was?
- 2) What were the properties of supportive nursing care?
- 3) What conditions led to supportive nursing care?
- 4) What were the consequences of supportive nursing care for patients, families and their nurses?

Comparative analysis of the data yielded two categories of supportive care identified by patients, family members, and nurses. As the interviews and concurrent analysis progressed it became apparent that these categories were interwoven or linked. The categories were: giving information and giving emotional support and physical/technical care. The order and manner in which these categories are

presented in the following pages reflects their chronological development through the concurrent interviewing analytic process.

Giving Information

Giving information emerged as a category from the interview data obtained from patients and their family members in discussion of the nature of supportive nursing care. The data used to illustrate this category were derived initially from the interview with Mrs. Roy and her family who identified a supportive nurse. Mrs. Roy and her family described both positive and negative aspects of care. Data from patients and families who were unable to identify a particular nurse as supportive were also analysed since giving information was one of the topics they discussed.

Excerpts from patient, family member, family unit, and nurse interviews will illustrate how the category of giving information arose from the data and how linkages to subcategories of explaining and knowing also surfaced. As well, they provided some understanding of how the consequences of these differed for patients and family members.

Mrs. Roy and Family

Mrs. Roy was a white haired, elderly French-Canadian woman who was sitting comfortably in her hospital bed at the time that I interviewed her. As explained in the chapter on Uncertainty (Chapter 6), Mrs. Roy and her family experienced uncertainty about whether or not to go to the hospital, uncertainty about what her symptoms meant, and about what to do about those symptoms. Furthermore, Mrs.

Roy's daughter was uncertain about whether her mother would call for medical help if something happened when she was at home alone. As identified in Chapter 7, Mrs. Roy's daughter felt guilty, worried, and responsible for taking care of her mother. Since Mrs. Roy's daughter worked full-time the only solution that she could see to this problem was to move Mrs. Roy into a nursing home where she would be supervised. This unilateral decision was based on limited information and led to family conflict.

In answer to my question regarding supportive nursing care during my interview with Mrs. Roy while she was hospitalised, Mrs. Roy recounted the following:

Mrs. Roy	Oh, they were good. Oh yes. They're good.
ER	Tell me what that means? What's good? How?
Mrs. Roy	They always look at you, do you need something? How do you feel? They're so nice.
Mrs. Roy	I don't remember her name, one yesterday, OH MY GOD (<i>strong emphasis</i>), she was so good. She explained everything to me and my daughter. Oh, they're all good anyway.

Mrs. Roy responded with the comment "oh, they were good". This general comment recurred frequently in subsequent interviews with other patients and their families and could be construed as a socially acceptable response. However, Mrs. Roy then qualified what she meant by "good" which included "looking at you", inquiring whether or not you "need something", and inquiring about "how you feel". "Looking at you" could be likened to being monitored or watched which was a property that surfaced in many accounts of both patients and family members and which for many led to feeling reassured (Mrs. Moore, Mrs. Pageau). Mrs. Roy used another socially acceptable word, "nice", to again describe nurses in general. Similar

to the “good” nurse descriptor, the word “nice” reappeared in many subsequent patient and family interviews.

Explaining. Later during this same hospital interview, Mrs. Roy further embellished on what she thought the nurse had “explained”. At first glance, the words “I didn’t know what to do” seemed simple. However, knowing the context within which these words were spoken provided some insight into just exactly how important the nurse’s explanation was for Mrs. Roy. Remember that Mrs. Roy had been hospitalised three times in the past three months. She and her daughter had expressed uncertainty about when to seek medical help (going to the hospital), about what symptoms meant, and about what to do about those symptoms. Furthermore, she had been at her daughter’s camp (summer home) when the episode that precipitated her current hospitalisation had occurred and it had been suggested that the increased activity associated with the trip to the camp might have contributed to her acute episode of congestive heart failure. However, if she followed the nurse’s instructions (that is, if she took her ‘nitro’ and rested once she arrived at the camp) then future hospitalisations might be avoided. The “I should have took” clause evoked an element of self-blame for being sick because she did not take the ‘nitro’ and ‘rest’.

Mrs. Roy	And, she said, if you try to be sore or something, don't forget your Nitro.
ER	Take that right away. Don't wait.
Mrs. Roy	Yes, don't wait. You can have four, five minutes apart, because she said, at your age, you don't have to, have, if you were at 40, well that's different, at your age. Try to live a good life.
ER	Yes. What else did she tell you? What other kinds of things?
Mrs. Roy	OH MY GOD, she told us everything.

She repeated what she said the nurse had told her about taking her “nitro” and “resting” at three different points during the interview. Each time she further expanded her understanding of when and how she should take the “nitro”. She said that the nurse told her lots of things that she had not previously known. The importance that she attached to this information is evidenced by these repetitions and by the way she associated taking the medication appropriately and resting with achieving the goal of ‘having a good life’ and going to her daughter’s camp. This information gave her the sense that she could control her illness if she followed these directions.

Mrs. Roy	Oh, the one I had yesterday was nice. She told me lots of things that I didn't know.
ER	That you didn't know?
Mrs. Roy	Yes, yes.
ER	And that will help you with looking after yourself?
Mrs. Roy	Yes, yes. Now I know, when I go to the camp, I'm going to take a pinch of nitro before I left and when I go back I'm going to go to bed.

In this last excerpt Mrs. Roy again said that the intensive care nurse was “nice” because she “told me lots of things I didn’t know”. The importance she placed on this information is evidenced by her repetition of these instructions followed closely by her announcement that she intended to follow the nurse’s instructions. There seemed to be a link between the patient not knowing what to do, the nurse explaining when and how to use the ‘nitro’ and when to rest, and the patient then using that information to gain personal control and achieve a desired goal (going to camp). The nurse that Mrs. Roy identified as being supportive had cared for Mrs. Roy while she was in the intensive care unit (ICU). I interviewed this nurse in the ICU before interviewing Mrs. Roy’s daughter.

During the interview with Mrs. Roy's daughter I wanted to determine whether or not she had been present when the nurse gave information to her mother. Since Mrs. Roy's daughter said that she was present, I asked her to tell me what the nurse had said and how she felt about that. I then looked for similarities and differences between the two interviews.

ER Were you with your mom when the nurse in the intensive care unit was explaining?
Mrs. Roy-D Yeah.
ER Can you tell me a little about what she said and how you felt about that?
Mrs. Roy-D Well, she said that, like she was saying, you know, like angina starts first, and then you get the congested heart failure. And then, she said, well, before you do something, like going up the stairs, you know. Take some nitro or before you take a bath, you know, use your nitro. Um, before you do anything that's going to be a little bit more hard on your heart. She said to use it because....it won't do any harm. No, cause my mom thought she could only use it twice and then that's it. Like somebody had told her that, I don't know who. And I didn't know too much about nitro myself so...so it's useful.

Mrs. Roy's daughter gave a much more detailed description of what she thought the nurse had said than Mrs. Roy did herself. Similar to Mrs. Roy she said that the nurse talked about using 'nitro' properly but she enlarged on that and added a variety of activities that she said the nurse indicated should be preceded by taking nitro. She then explained that the nurse had also corrected a misconception held by her mother about how frequently 'nitro' could be used. She ended her description of what the nurse had explained by relating that previously she "didn't know too much about nitro" and saying that the information given by the nurse was "useful". On the other hand the patient, Mrs. Roy, culminated her description of supportive nursing care by focussing on her personal goal of "going to camp".

Later during the same interview with Mrs. Roy's daughter I asked her what she thought supportive nursing care was.

ER What would you say supportive nursing care was?

Mrs. Roy-D I don't know what it is. Well, I know that the nurses in ICU are very nice. Like they explained, you know, a lot to her, especially this time. They didn't so much, the last time she was there. But this time, I guess they're very busy too, in there, and it just happened that one day that they had, I think about four patients. So, there was three nurses. So, they had more time to...so, she (*the nurse*) really, really sat down and talked to her. But, I don't think they have a lot of time. You know, like to sit with the patients.

She initially responded by saying she didn't know what supportive nursing care was but she quickly then said that the nurses in the intensive care unit (ICU) were "very nice". She seemed to link very nice with the nurse really "explaining a lot" to Mrs. Roy. However, she qualified the act of "explaining a lot" by indicating that this had not happened during previous hospitalisations. She thought the giving of information occurred because the nurses weren't as busy that day. There were fewer patients in the unit and thus there was time available for the nurse to sit and talk with Mrs. Roy. Patients and family members and nurses themselves in many other interviews frequently raised the issue of "time" and "being busy" as barriers to providing supportive nursing care. Her repetition of the word "really" placed emphasis on the importance of the "talk" given to Mrs. Roy and her daughter by the nurse. Later during the interview Mrs. Roy's daughter expressed uncertainty about whether or not her mother would call for help when left alone and her sense of being responsible to make sure nothing happened to her mother surfaced. Who would look after her mother during the day after discharge? She had not told anyone of her concern and had received no discharge information about available community resources from the nurse. The following excerpt illustrates these points.

ER	Has no one said anything about you worrying about discharge?
Mrs. Roy-D	Yeah, nobody.
ER	Oh! So, have you talked to the...has anyone said anything about discharge or how she can manage at home?
Mrs. Roy-D	No.
ER	Has no one said anything about you worrying about discharge?
Mrs. Roy-D	Yeah, nobody.

ER Do you think it would help to have somebody to talk through some of these things, like figuring out where to go and what you should do at discharge? Kind of sort some of those things through?

Mrs. Roy-D Yeah. Well, like I'd like to know if there's anybody that you can hire. Somebody like to come and stay with her or...

ER It's pretty much managing a course of action that you can feel comfortable with yourself and that your mom's comfortable with? And support from other family members in that decision? Your sister will be from what you just said to me (*Mrs. Roy-D interrupts*)

Mrs. Roy-D I need it, she's coming home today.

Mrs. Roy's daughter was often brief in response to my questions. She had a harrassed, worried expression on her face and she cried several times during the interview. She desperately wanted help to solve the problem of who would take care of her mother during the day when she was at work. At this point the doctor had not given her any direction and the nurses, except for the ICU nurse, had also not given her any information. Her sense of responsibility for caring for her mother was overwhelming and she needed help now.

The granddaughter was also interviewed in her mother's home while Mrs. Roy was still hospitalised. The granddaughter had been alone with Mrs. Roy the evening of the first of the three episodes that led to her hospitalisation. This first episode occurred at night during a bad winter storm through which the granddaughter had driven to transport Mrs. Roy to the hospital emergency room. The granddaughter said that no one at the hospital had explained to her what was happening to her grandmother. The only contact that Mrs. Roy's granddaughter could recall occurred when she was asked to sign a treatment consent form. She was left sitting alone in the waiting area for two hours. When I asked this granddaughter what she thought supportive nursing care was she responded as follows.

ER In all the time that...the three times this year that your grandma's been sick, have any nurses talked with you?

Mrs. Roy-GD No.

ER No? If I asked you what supportive nursing care means...
 Mrs. Roy-GD Yeah, I wouldn't know.
 ER You wouldn't know?
 Mrs. Roy-GD Yeah.

This granddaughter had no contact with nursing staff beyond signing a consent form and reported no interaction with nurses and had no idea what supportive nursing care meant. In interviews with other family members (Mr. Martin's son, Mrs. Levesque's daughter, Mr. MacKenzie's son) this same lack of interaction was described. These family members who were sons and daughters of patients but not primary caregivers received little or no information from nurses. This raised questions about why this was happening. Perhaps the further apart the relationship between patient and family member, the less contact the family member has with nurses and the less information they receive. Or, perhaps there was no one available to talk to Mrs. Roy's granddaughter because of the acuity of other patients in emergency. In later interviews with other patients, families, and nurses I tried to explore this issue further. Why didn't nurses talk to family members and offer informational support?

Mrs. Roy's Nurse

Mrs. Roy's nurse worked in the ICU and had cared for Mrs. Roy for a couple of days while she was a patient in ICU. She was an experienced ICU nurse who had worked primarily in intensive care settings throughout her 25 years of practice and who had also taught intensive nursing care courses at the local college. Profiles of the nurses interviewed in this study can be found in Appendix A (Table 2). Prior to beginning the interview I told her that Mrs. Roy had identified her as a nurse who had

given “supportive nursing care”. Mrs. Roy’s nurse had the following to say when asked to tell me what she thought supportive nursing care meant for Mrs. Roy.

Mrs. Roy-N Hum, supportive, hum. Making sure that they're physically, their physical needs are cared for initially. Comfort, chest, lungs, make sure they're breathing well. Once we're over that, someone like Mrs. Roy, in particular, we need to make sure they know how to take care of themselves. That they understand what their disease process is and how to recognise what's going on. The family as well, because she's living with the daughter. That's support.

Initially this nurse talked about supportive nursing in general terms. She provided a list of what she did for this kind of patient. The order of items on this list was important. I later confirmed with her that in her view “physical needs came first”. The nurse referred to Mrs. Roy using the generalisable pronoun “they’re” possibly suggesting that physical care was a phenomenon generalised to the care of other patients in a similar situation. She then outlined care that was peculiar to “someone like Mrs. Roy”. She was again generalising because care was not for Mrs. Roy but rather for someone “like Mrs. Roy”. She said that she included family in “knowing what their disease process is and how to recognise what is going on” because she knew that Mrs. Roy lived with her daughter. She made it quite clear that “once you get her over that (the physical problems) then you work on the rest.”

Mrs. Roy-N Now, once you get her over that, then you work on the rest. Because, obviously she's been in the hospital frequently. So, they're obviously misreading her symptoms, and then she gets into an acute situation and it's already too late. Had they recognised things ahead of time, I'm sure she'd manage a lot better and would have fewer admissions.

The nurse did not link Mrs. Roy’s frequent hospitalisations to her deteriorating heart condition but rather to “misreading symptoms”. The importance the nurse attached to “misreading symptoms” and being “misinformed” about the appropriate use of ‘nitro’ surfaced three times during the interview, signalling the importance she

attached to these behaviours. There was an inference of 'blame' that lay just below the surface. However, the reader is reminded that Mrs. Roy did have difficulty in making the connection between being short of breath and her chronic heart failure which was illustrated and analysed in Chapter 6. But her heart failure had also progressed so that hospital readmissions were not just the consequence of "misreading" symptoms. Her lasix dosage had been doubled and the cardiologist had told Mrs. Roy's daughter that she had progressed from a heart working at "39% of it's capacity to "25%". The daughter was given this information by the doctor accompanied by "it won't be long now" the inference being, until she died. Whether or not the nurse was aware of the information given to Mrs. Roy's daughter concerning Mrs. Roy's prognosis was unknown.

I knew that Mrs. Roy had difficulty making the connection between increased fatigue, difficulty breathing, and her heart condition and so I asked the nurse how specific she had been in helping Mrs. Roy to understand what her symptoms meant. The following quote illustrates the specific kinds of information the nurse said that she gave to Mrs. Roy and her daughter.

Mrs. Roy-N Uh, I was very specific about the early onset of the kinds of symptoms she should recognise. Hum, not being able to lie down flat, having to have extra pillows and hum, finding she's more tired then usual. All the kinds of things that they might not think are markers but are.

The marker that Mrs. Roy remembered from the information she received from this nurse was 'being tired'. Neither Mrs. Roy nor her daughter made reference to not being able to lie down flat or having to use extra pillows as being markers or early

warning signs of impending failure. I asked the nurse how the information that she gave to Mrs. Roy and her daughter was delivered. Her response follows.

ER And in the unit here, do you guys use any kind of written information or is it mostly verbal?

Mrs. Roy-N We have a book on congestive heart failure and I went to find it. It was a little teaching manual we used to give our patients in coronary care and I couldn't find it here. It may be in another spot because the floor has taken on a lot of this post...uh the intensive care teaching. So, they may have it down there. I couldn't find it here. But we have one specifically on the problems and symptoms of congestive heart failure.

The lack of written information about congestive heart failure was a problem for this and subsequent patients and their families (Mrs. Brunette, Mr. Peterson, Mrs. Levesque, and Mrs. Houle). The nurse referred to an information booklet later in the interview and expressed guilt at not having the time to find it for them. None of the patients or families interviewed saw or received this booklet. I learned from nurses on the floor that the booklet was not available.

When I asked the nurse what she thought supportive nursing care was for Mrs. Roy's family she responded as follows.

Mrs. Roy-N Well, support care is hum, talking with the family at the bedside and away from the bedside. They need to know.....hum, things that hum, it's one of the things we do a lot you know. You can educate them, you give them information, you hum reassure them, hum, and tell them the truth. God, there's so many of them hum, that don't know, really what things mean. What's real, you know. They haven't really faced it, denial or whatever.

Her response was generalised to "the family" as opposed to focused on this particular family. She listed her beliefs about the standard sorts of activities she undertook with families in general. These included educating, giving information, giving reassurance, and telling them the truth. These activities did surface again in interviews with subsequent patients, their families, and their nurses (Mrs. Levesque, Mr. MacKenzie, Mrs. Moore).

The nurse provided this patient and her family with relevant, useful information on the use of nitroglycerine and the connection between activity, rest, and heart failure. However, there was no written reinforcement; communication with floor nurses involved a verbal report and whatever appeared on the “kardex” and “nurses notes”. In the past, the nurse from the coronary care unit had met weekly to discuss patients and there was also a liaison with the public health nurse on a monthly basis. Changes in health care delivery in both the hospital and the public health system have led to the cessation of the public health liaison meetings.

Mrs. Roy-N We're not involved in them (*weekly meetings to discuss patients*) anymore because we just don't have time anymore. And workload. Workload. We don't only have cardiac anymore. We have the big surgeries, big neuro cases and so our workload is so heavy we don't have time to just sit and chitchat anymore.

The issue of excessive workload which limited the time available to give supportive nursing care that involved information giving resurfaced repeatedly in interviews with other patients, family members, and nurses. Providing patients and families with relevant needed information as presented by Mrs. Roy's nurse was not as important to this nurse as giving care to “big surgeries” and “big neuro cases”. Despite her descriptions of giving needed information to this patient and her daughter that seemed to emphasise the importance of the information, the nurse ended the interview by inferring that talking with patients and families about the management of their illness was “chitchat”. The word “chitchat” evokes images of idle chatter. Relegating the giving of relevant, needed information to “chitchat” perhaps denoted the low value placed upon such activities. Information giving seemed not to be valued when compared to the more complex care required by other patients in her

care. However, highly complex, technical care is the reality of an intensive care unit. Are information giving and emotional support incompatible with the provision of physical care? Complexity of care was a reality that both Mr. MacKenzie's and Mrs. Moore's nurses affirmed and expanded upon and will be further discussed in the pages ahead. This nurse's comments led me to pursue this issue with other nurses. Was there really no time to talk with patients and families and to give needed information to patients and their families?

The Roy Family

From the data collected at the family interview, which occurred in Mrs. Roy's granny flat approximately four weeks after she was discharged from hospital, further issues surfaced around the giving of information. The family interview involved Mrs. Roy and her daughter.

- Mrs. Roy-D The only thing when she was discharged, like they didn't give her the nitro patches, when she was discharged....
- ER Uh, huh.
- Mrs. Roy-D And what else, there was something else. Oh, they had cut your thyroid eh? For three days.
- Mrs. Roy Yah.
- Mrs. Roy-D Thyroid pills.
- Mrs. Roy And they give me, they give me a new kind too, the last time I was here.
- Mrs. Roy-D Oh yah. And like, the paper (*discharge instructions*) I was looking for there, didn't have her nitro written on it, didn't have....like I asked the nurse, well what is she supposed to do? Like, is she supposed to go back to the nitro patch? Cause she had it in the hospital. And then, the nurse said, well normally you do what you were doing before you came in the hospital. But then they (*the doctors*), they gave you (*speaking to Mrs. Roy—looking to her for confirmation of what she is saying*) another one? They cut something out, they added something. This one's a lasix, twice a day. I go, well, what do we do? Do we stay with what's now or what's before? or you know. So, anyway she said, maybe you should call your doctor. So, I went to the drugstore cause she had to get some other stuff and the pharmacist called the doctor. So, it got cleared up. And, she (*the family doctor*) said, well, stay on your nitro plus whatever you were taking in the hospital. So, that was a little bit, a little bit of a misunderstanding that wasn't very clear like you know.

Mrs. Roy's daughter displayed her distress at the conflict between the medications written on the discharge form by the floor nurse, the medication Mrs. Roy was receiving while hospitalised, and the verbal directions given by the floor nurse. The constant question form of her account is interesting and perhaps reflected the uncertainty Mrs. Roy's daughter was experiencing. The absence of information about the "nitro" was particularly distressing for Mrs. Roy and her daughter. As recounted earlier, the ICU nurse had spent considerable time explaining the appropriate use of "nitro" to both Mrs. Roy and her daughter and both the patient and her daughter placed great importance on this information. The discharge nurse's reported comment, "Well, normally you do what you were doing before you came to hospital" was not helpful because it led to further confusion – "well, what about the Lasix?" According to this patient's cardiologist, Mrs. Roy's heart condition had deteriorated and hence the diuretic (Lasix) medication had been increased. The dose that she had been taking prior to hospitalisation was no longer sufficient to keep her heart failure under control because her illness had progressed. Consequently, telling the patient to go back to what she was doing prior to hospitalisation was an inappropriate suggestion. Fortunately, Mrs. Roy's daughter recognised something was wrong with this advice. Although the nurse's suggestion that Mrs. Roy should call her doctor was not a bad one, it was not directly acted upon by Mrs. Roy's daughter. Instead, she consulted the pharmacist who sorted out the problem by calling the doctor and having the order clarified. Mrs. Roy's daughter had told me during an untaped conversation after my individual interview with her that she was having a terrible time with both her mother's and her daughter's

doctors. One had quit his practice and the other was difficult to gain access to because his receptionist screened his calls. Hence, Mrs. Roy's daughter had a history of not being successful in 'calling the doctor'. The discharge nurse from Mrs. Roy's daughter's perspective, had limited knowledge of Mrs. Roy's illness condition and was unaware of Mrs. Roy's daughter's unsuccessful attempts at accessing doctors. Her advice was incorrect, ineffective, and ignored. However, it should be remembered that in this situation only the views of the patient and family were represented. It would have been interesting to have heard the discharge nurse's perspective but that was beyond the boundaries of this study.

The need for clarity and accuracy of the information given by the discharge nurse was of particular importance to the daughter who felt responsible for making certain that her mother's medications were correct. The only written information Mrs. Roy and her daughter received pertained to Mrs. Roy's medications and that information was not helpful because it was confusing and incorrect. Mrs. Roy's daughter worked and she was afraid to leave her mother alone during the day because she was uncertain about whether or not Mrs. Roy would call for help should medical problems recur. Her uncertainty and fear were not identified and no referrals to existing community resources were made. In contrast, the information given to Mrs. Roy by the ICU nurse gave her a sense of control and was seen as useful by Mrs. Roy's daughter.

Another patient, Mrs. Levesque (see Family Profiles, Chapter 5), also identified a nurse who gave supportive nursing care by giving information. In describing how a particular nurse gave supportive nursing care, Mrs. Levesque spontaneously

contrasted her positive experiences with a cardiac rehabilitation nurse with negative accounts of care she had received during a recent hospitalisation. Both positive and negative accounts are represented here to help in furthering understanding of supportive nursing care in the context of information giving.

Mrs. Levesque and Family

My interview with Mrs. Levesque took place in her home approximately two weeks after she had begun participating in the cardiac rehabilitation programme. According to Mrs. Levesque the nurse at the cardiac rehabilitation programme was the first person to ever explain her cardiac illness to her.

ER So, can you tell me about what the nurses have talked to you about up at cardiac rehab?

Mrs. Levesque Oh, she show me my heart on a paper and everything. And she explained to me why the doctor doesn't want me to drink too much water. Oh yeah, they're nice! You ask them anything, you know, they they tell you. And I have a young nurse yesterday- what is congested heart failure?

ER Um hum, um hum. Nobody had explained that to you?

Mrs. Levesque No. When the doctor. I didn't even know that was what I had when I went into the hospital. But when I went to, to uh, register (*at cardiac rehab*) the, the nurse said, well oh, with all those medications she said, it was uh cardiac eh, congested heart failure.

ER Yeah, yeah. So now do you know?

Mrs. Levesque Eh, the nurse told me. It's like when all the water is there it is hard on the heart. He (*the heart*) has to work harder.

In the above excerpt, Mrs. Levesque described the specific activities of the nurse who she thought had given her supportive nursing care. This nurse gave Mrs. Levesque specific information about her heart (showed her a picture of her heart). Similar to Mrs. Roy, Mrs. Levesque was given explanations and information by the nurse that she had not previously received. Mrs. Levesque's explanations of her illness were simple ("the heart he has to work harder") but they were accurate and

reflected understanding of her illness which she attributed to the supportive nursing care she had been given.

Knowing. Later on in the interview Mrs. Levesque again talked about how the nurse explained everything to her. She also emphasised that the nurse initiated the discussion by asking her whether or not she knew what had happened to her heart.

Mrs. Levesque And when I go for the exercise (*to cardiac rehabilitation*) the nurse, they got all you record (*medical records*) there. Cause she asked me. She said, did you know what happened to you? And so, then she had the picture of the heart and everywhere here's lines you know, there is blockages and that. And she explained like -- sometimes the neighbours they take water pill and they take potassium and all that. You gotta drink lots of water. And they don't understand, that the doctor don't want you to drink water. They don't know. But I know now, you know. Cause uh, okay once in a while I'll go and take a sip. But I mean, before I would drink a big, big glass. But I don't now! So, and it's better to listen to the nurse and to the doctors than neighbours, you know. Cause uh, they say well my brother was like that, my sister, but maybe it's not the same thing. Yeah.

Mrs. Levesque painted a very positive picture of the information that she had gained from the nurse at the cardiac rehabilitation unit. "The picture of the heart" refers to the results of Mrs. Levesque's angiogram which the nurse showed to her to illustrate the blockages in her coronary arteries. The nurse went on to discuss her water pill, potassium, and consumption of fluids in relation to her heart function. Mismanagement of each of these aspects of treatment can have life-threatening implications for Mrs. Levesque. Equally important was Mrs. Levesque's understanding that she should follow the information given by the nurse and doctor rather than the advice of neighbours. Mrs. Levesque's serious tone of voice and her ability to recount this critical heart failure management information seemed to illustrate the high value she placed on this supportive nursing care.

However, after describing her positive experience with the nurse in the cardiac rehabilitation unit, Mrs. Levesque also gave accounts of care that she had received during a recent hospitalisation that were not supportive.

- ER So, tell me a little about the kind of nursing care you got when you were in the hospital?
- Mrs. Levesque Oh, not too good!
- ER Not too good?
- Mrs. Levesque No.
- ER What happened?
- Mrs. Levesque She gave me a needle. I had the intravenous. Just before she went for her break and my God did it ever hurt. I felt like ripping it out, I thought that maybe it went between (*interstitial*) you know. And then, when she came back, I told her, I said, OH MY GOD THAT NEEDLE HURT. Oh, she said, I should have told you it was potassium.
- ER It burns?
- Mrs. Levesque Yeah! So I, if she had told me, you know, it's gonna burn a little bit, well. But I, but I mean they don't have as much time as they need you know with all the cuts and that too. So you can't blame them too much. I understand that. But

These data are relevant not because the picture painted was a negative one but because in telling me about what wasn't supportive, she indirectly illustrated what she thought was supportive. For example, the nurse did not give her the information to expect pain.

Mrs. Levesque's Daughter

Mrs. Levesque's closest family member was her daughter and the two were very emotionally close to each other.

- ER Did you get a chance to go in and visit much?
- Mrs. Levesque-D Yeah, yeah I did. But even then I'd try to talk to the nurses but they'd use such big terms and I even called our doctor here and he really didn't want to because he wasn't a heart specialist. So. And to try to talk to them was ... hard.

The daughter had no knowledge or understanding of what was happening to her mother. Her eyes widened and her lips trembled as she described how she had tried to get information from the nurses on the floor during her mother's recent

hospitalisation. After several fruitless attempts to talk with a doctor she said that she was finally able to make an appointment and meet with the head nurse who explained to her mother's heart condition to her. However, after such a desperate struggle to get information about her mother's illness, her care and medications and so on, she did not understand what the nurse told her. She said to me in a muffled voice, "I couldn't understand what the head nurse said to me. She used such big words." She didn't understand the explanation.

When I interviewed her at her mother's home more than six weeks after her mother had been discharged from the hospital, she still did not understand her mother's illness or medications and wanted information from me. She worked full-time and had been unable to attend the education sessions at the cardiac rehabilitation programme.

In summary, giving information was a category that came from the data. Properties of giving information included explaining and knowing. Properties of information included clarity, accuracy and honesty. Conditions that led to giving of information included the patient and/or family asking for information, the nurse having the time and valuing the activity. Consequences of receiving information were a sense of control for the patient and information was perceived as useful for the family member. When information was not provided or not understood then confusion and family conflict occurred.

Giving Emotional Support and Physical/Technical Care

Emotional support and physical care emerged from the data as categories of supportive nursing care. The need for emotional support and physical care emerged from many patient and family interviews. However, Mr. MacKenzie's depiction of this need was particularly informative and poignant. He portrayed an individual who knew he was dying, expressed uncertainty about when and how he was going to die, and sought emotional comfort from nurses.

Mr. MacKenzie and Family

When I interviewed Mr. MacKenzie he had been hospitalised in the ICU on an elective basis to have his medications adjusted. His expressions of uncertainty and fear around "when and how am I gonna die" have been explored in an earlier chapter that focused on the core category of Uncertainty (Chapter 6).

Mr. MacKenzie's uncertainty and fear of dying was strongly coloured by his experience with his wife's death from throat cancer five years earlier, information that Mr. MacKenzie volunteered. He said that she had experienced a lingering illness full of pain and suffering. During separate interviews, both he and his son spoke in voices filled with sorrow, of caring for her at home as though it had happened yesterday. Excerpts from interviews with Mr. MacKenzie, his son, and his nurse resonated with his need for emotional support. He began the interview by giving the following description of what he thought a supportive nurse would be like.

Mr. MacKenzie Well, I found the one that was on yesterday, very compassionate. Like uh, we look at the nurses for their help of physical care but we also look at them for their attitude in relaxing us and making us feel comfortable and welcome which is more important many times than nursing.
ER The physical care?

Mr. MacKenzie The physical care, the emotional care is much more important or at least just as important.

Mr. MacKenzie immediately identified compassion as an attribute of supportive nursing care. He then indicated that nurses give physical care but “the emotional care is much more important or at least just as important.”

Listening. When I began the interview with Mr. MacKenzie the first thing he said before I even asked a question was “I didn’t shave”. I responded by saying that it didn’t matter to me whether or not he had shaved. If he did not feel like shaving that was fine with me. ‘Not shaving’ became the vehicle through which he explained to me what he thought supportive nursing care was.

Mr. MacKenzie Yeah, you know somebody who makes you feel relaxed and welcome. I remember, I was at the, uh, at this hospital, uh yeah, and a few days before surgery, I found out then, I was gonna lose the leg, you know, and I was, I wasn’t, I wasn’t shaving like this and there was that one nurse, she was so darn mad at me.

ER Because you didn’t shave?

Mr. MacKenzie Well, she said, I don’t take care of people who don’t take care of themselves. And I said, yeah. But, I said, I’m just feeling a little bit down right now. And uh, and she give ah, nooo. And I didn’t think it was the right attitude.

Mr. MacKenzie Yeah, I said, yeah, I told her, put yourself in my shoes. You know, I just didn’t want to do nothing.

Mr. MacKenzie They gotta put themselves in the patient’s shoes. You know, you’re going through surgery tomorrow cut your leg off! What are you gonna, you know?

ER You want me to shave?

Mr. MacKenzie Shave? You know what I mean?

Mr. MacKenzie Cripes! Things like that.

In the above excerpt Mr. MacKenzie described a situation that occurred during his last hospitalisation when his leg had been amputated. He had not been forewarned about the possibility of a below-knee amputation. He came into the hospital and was told just before surgery that his leg had to be amputated. He tried to explain to the nurse that he was “feeling a little down”. She could not put herself in his shoes and instead told him she did not look after people who did not look after themselves. Mr.

MacKenzie used a negative account to emphasise what he thought supportive nursing care was: listening and having empathy. Mr. MacKenzie then went on to further expand on what he meant by compassion, what I have since labelled empathy.

ER Um hum. Now, you said the nurse yesterday was compassionate. Can you give me an example of what you mean by that?

Mr. MacKenzie Oh, she was very understanding. She, she listened to me just as much as I listened to her. You know.

ER Um hum. So, she listened?

Mr. MacKenzie She was a good listener, exceptionally, good listener. Yeah, yeah. And I told her, I told her! She was, it was a pretty good character trait for critical care patients. Real good listener. That's all. And it's really not hard to listen. But it is hard.

Mr. MacKenzie It is hard (*laughing together*). It is hard. Can be very hard unless it's, you're told over and over or unless you understand that feeling.

ER Learning to put yourself in the other person's shoes?

Mr. MacKenzie Yeah, yeah. If they can put themselves in the other person's shoes. Yeah, then they're good listeners.

Empathy was depicted by Mr. MacKenzie as the nurse "being very understanding" which he then linked to "listening". He repeated variations of the word "listen" many times and then amplified by saying that being a good listener is easy but at the same time it's not easy. You have to work hard at listening. It's hard to understand how another person feels unless you have experienced the feeling yourself. He suggested that nurses have to be told many times "over and over" or sometimes they "understand the feeling" if they can put themselves in the other person's shoes.

Mr. MacKenzie You look towards understanding. You look towards the nurse understanding you. More than anything! You know, that they want to listen to you, for the little few things you say. You sort of get a feeling in the first uh, five minutes whether the nurse is going to listen to you or not. Just takes a few minutes. She can either relax you or she don't.

ER How does she relax you?

Mr. MacKenzie Well, she might ask you a simple question. How are you feeling? You know. Are you feeling fairly comfortable? or, you know.

Mr. MacKenzie A lot of nurses aren't that, that little touch that you need. It's really, I guess, they don't understand it. To them, certain nurses look at it as a job and that's it. And they're good at it! But they don't figure the emotional feeling is very important, that you convey to patients.

ER Um and you can tell that?

Mr. MacKenzie Oh, you can tell that. A patient can tell that, just like that (*snapped his fingers*). It ain't. Oh, you can tell if somebody's interested in you—in you, your pain, or your worries. Sure, that's important. Yeah. Everybody wants to have somebody interested in them. In their troubles, about their pain. I made out a written will already. I talked to the nurse a little bit about it. She told me to give a copy of it to the doctor. And to your heart specialist, which I didn't you know.

ER The nurse sounds like a pretty terrific person.

Mr. MacKenzie Good listener.

Understanding arose from the nurse listening to what the patient said. The supportive nurse wanted to listen and the act of listening led to Mr. MacKenzie feeling “relaxed”. The simple question “how are you feeling” provided him with the opportunity to talk. This question was also raised by other patients (Mrs. Roy and Mr. Peterson). Many patients and families did not initiate contact, they waited to be asked. Mr MacKenzie said that a lot of nurses are not interested in listening or in providing patients with emotional comfort because they do not see that as part of their job. He described how he could tell whether or not a nurse would be emotionally supportive. Mr. MacKenzie said that a supportive nurse could be detected quickly because she was “interested” in his “pain, troubles, and worries”. He then gave an example of supportive nursing when he described the nurse who listened to him when he told her about his living will and she then advised him to give copies to his family doctor and his heart specialist.

Mr. MacKenzie's Son

Mr. MacKenzie's son could not talk about what he thought supportive nursing care meant for his father without constantly referring to the experience that he, his sister, and his father (Mr. MacKenzie) had gone through at the time of his mother's death. Like Mr. MacKenzie himself, he could not talk about his father without making constant references to his mother's illness and death. This man was an articulate, university-educated businessman who had taken a leave of absence from

his work so that he and his sister could provide around-the-clock tracheostomy care for their mother at home during the last month before she died. I did not attempt to extrapolate the responses he made that did not directly relate to his father because I felt that would be a misrepresentation of the context in which he saw his father's care. Unfortunately, I was unable to interview his sister who lived 200 miles away and who was considered by both Mr. MacKenzie and his son to be Mr. MacKenzie's primary caregiver. The following excerpt is Mr. MacKenzie's son's response to my question about what supportive nursing care was for his father.

Mr. MacKenzie-S Okay, I, I think the nurses have done a very good job. Um, looking back um over the last number of times that I've been in the hospital with him I've seen the nursing staff, how they've supported him. I think they've done a very good job. What I did see uh, perhaps over the years since when my mom first became ill. I'd be hardpressed to come up with the exact date when that happened. I've seen a gradual decline in the nursing care that people have been given and I think it's mainly caused by the fact that nurses are so much more busy. They don't have as much time to do, uh to talk with people, to talk with patients. Talk with families. And I've seen a marked change in that. So, that's probably going back over a five year period. Um, but as far as, what I've seen the nurses do with my dad in the last two years, you know interactional support, I think it's been very, very good. Uh, I, I feel that the nurses have been put in a very awkward position and uh they're basically burning the candle at both ends. They don't have the extra time they might have had before to uh, spend with patients. And um, maybe at times they might be a little bit short (short-tempered) but that happens very, very seldom, you know, it's so rare. But I can understand why that it might be that way for the patient. So, what I've seen in general though is that the nurses have really been doing an excellent job. So, they were supportive in the fact that they didn't um make us feel more depressed with the issue. I mean, they weren't dancing around, jumping around, you know, with glee but they were, but they were supportive. They weren't um um, they were there for the most part when we needed them.

Similar to many other patients and family members, Mr. MacKenzie's son placed importance on "talking with patients" and "talking with families". He repeated several times during the interview that being supportive meant "talking with patients and family members" and doing so with a "positive attitude" but at the same time not giving false reassurance. Throughout the interview he focused on the nurse

providing emotional support to the patient and to the family. He frequently spoke of his mother's illness and would then link that to his father's current situation.. He felt there had been a decline in supportive nursing care and attributed that to health care cutbacks. He felt nurses were "burning the candle at both ends". He repeated and emphasised the importance of "interactional support" provided by nurses. Although he politely let me know that not all nurses were supportive, some in fact were "short" (short tempered or angry) with patients. However, he qualified this criticism by suggesting it was "rare" and that in general he thought the work nurses were doing under difficult circumstances was "excellent". In subsequent parts of this interview, he referred several times to nurses being "busy" and related this to "health care cutbacks".

Mr. MacKenzie's nurse and other nurses seemed to operate under the assumption that if patients or family members did not ask them questions then they had no concerns. Mr. MacKenzie's nurse said during her interview that "if family members didn't ask any questions then they seemed okay". This statement implied that contact with family members only happened if they asked questions. Since earlier family members and patients went home from the hospital without needed information (Mrs. Roy, Mr. Peterson, Mrs. Levesque, Mrs. Brunette), I wondered if this happened because patients or family members didn't initiate contact by asking the nurse questions. So, I incorporated a question and asked Mr. MacKenzie's son if nurses had ever approached him to talk about his care. Analysis of Mr. MacKenzie's son's response provided some insight into the issue of why some patients and family members do not receive illness information for the management of patient care. If

patients and family members did not directly ask for information or for emotional support it seemed that such care was not provided. There seemed to be a link between giving information and providing emotional support to patients and families. I tried to explore this aspect of information giving and emotional support with Mr. MacKenzie's son in order to further develop these categories.

- Mr. MacKenzie-S We always initiated contact. Um, in fact, I can't recall a situation where the nurse actually initiated the contact with us to explain how it's being organised.
- ER Do you think that's important? Or does it matter or?
- Mr. MacKenzie-S I think it would actually be um, I think it is important. Um, it would basically show uh, that the nursing staff give the uh care, you know, family care, and care for the patient, um. I think from what I've seen, I've seen nurses explain what they're doing quite well. And they're very thorough on that.
- ER What they're doing and why they're doing it?
- Mr. MacKenzie-S Yes, yes exactly. That's um, you know, that's you know. I think the question you asked about having a nurse approach us to talk about the patient, to explain the situation you know or what's happening.
- ER To ask you how you're managing or you know what will go on at home or?
- Mr. MacKenzie-S Yeah. No, no that, that, I don't recall that happening at all, when my mom was ill and I don't recall it happening since my dad's been ill. So, taking it, taking it for the quality of his health right now. They're just pressed so hard they can't afford the time.
- ER Um.
- Mr. MacKenzie-S But um, it would probably help because they are much more in tune with the medical side than we are um and with the quality part of health.

Mr. MacKenzie's son appreciated the ability nurses have in "explaining" patient care and suggested that they know more about the medical side of it and understand the "quality of life" issues so they should initiate contact with family members and they would be able to decipher or interpret the medical jargon to family members. He suggested nurses do not do this because they are "so hard pressed for time".

Mr. MacKenzie's ICU Nurse

Mr. MacKenzie's nurse was a bright young nurse who eagerly participated in the interview. She had worked on a surgical floor before transferring into the ICU.

Mr. MacKenzie-N I think, supportive nursing care is his medical condition and explaining all of that to him, a lot of education about his medications and where his condition is going, his prognosis and being there when the doctor comes in and talks to the patient, so that you are both on the same wave length and you can tell everybody what the doctors say, explain things and uh.

ER Can you think of a specific example of something that you've done that you think was supportive to him as a patient?

Mr. MacKenzie-N Um, in this gentleman's case he's basically been told that you know his condition at this point is really, is really terminal. Like, what he's in for now is kinda of a pep up, as far as the drugs go and probably, we'll probably see him in another couple of months for the same kind of thing, just so that we can. Surgery isn't you know, an option or anything for him, at this time. And him dealing with that you know is pretty scary stuff.

ER Uh huh. It's pretty much palliative?

Mr. MacKenzie-N Yeah, it is. So, that's you know, he's kinda come to terms with that and he's very good about it. He doesn't delude himself into thinking that uh, he's gonna get a whole lot better. He'll have highs and lows and he knows that. And that's probably, with him that's probably the most supportive thing.

Through the interview she stressed at least three times that the focus of care, the priority was the patient. Care was "more directed at him and his health versus his family". She also said that unless patients were in ICU for a long time "you don't really see family" and "so, mostly its the patient's needs that come first." She repeated several times during the interview that the focus of care was the patient. Family is mere context—if family members have questions or cause problems then they are attended to and she recorded and shared that information with other nurses. She made it very clear that not all nurses do this. She talked about information giving, explaining equipment, and giving emotional support to the patient as being supportive nursing care. This nurse saw supportive nursing care as providing the patient with information about his condition and interpreting what the doctor said to the patient and to other team members. She did not directly say that Mr. MacKenzie was dying, she used the more objective, clinical phrase "he knows that he is terminal".

I asked this nurse if she could tell me other kinds of care she gave to Mr. MacKenzie in his critical, chronic illness situation. Her response was as follows.

Mr. MacKenzie-N Um, there's a lot of emotional kind of support. And education kind of stuff. I mean, to let them know what's going on and just to listen to them when they want to talk about what's going on.

ER How do you give emotional support?

Mr. MacKenzie-N Listen most of the time. Tell them it's okay to be scared. It's okay to be worried. Or uh, that ties in a lot too, you know, if they want to know about their condition or where it's gonna go, or what's gonna happen to them. Going back to why everything has happened to them. What all the equipment is. Um. There's a lot of other types, you know, like making them feel better emotionally but mostly it's kind of being there occasionally and letting them tell you, tell you what's on their minds which is one nice thing about critical care. You've got more time for patients than you do out there (*on the floor*) so that you can do that.

Immediately she linked emotional support and education. Giving "them" information and "listening" to them. She said she gave emotional support by giving patients permission to tell her things and suggested that there was time to do that in ICU but not on the floor where nurses had to care for ten to twelve patients.

ER Is there any way to more effectively deal with that time issue?

Mr. MacKenzie-N I think if you had something like a specific. I don't know, even a checklist or something that you actually had to go through certain things and document. Even if it was just done once in the whole hospital stay, you know. At least if there was certain areas that everybody knew about then it could be, you know, addressed.

ER Then people might not slip through the cracks?

Mr. MacKenzie-N Well, that's it. Because I'm sure there's lots of people that do it all anyway and there's probably people that wouldn't do any of it and then there'd be most people who would be somewhere in the middle. (*people = nurses*)

ER So if it's tied into the system?

Mr. MacKenzie-N Yeah and if there was actually something you know physically documented.

ER Yeah, like you have to record blood pressure so why not record this too.

Mr. MacKenzie-N Yeah, exactly. Yeah, cause I'm sure that the physical stuff, I don't know, but I'm sure it would always take priority and that if there's a lot of that going on then the other stuff will probably get left by the wayside, for sure. Like, I mean if you look at the flow sheets there's nothing in there about how they're feeling, there could be. Or, you know, there could be a little box there for that too!

She attached some importance to being held accountable for providing emotional support. She suggested that even a check list could be helpful, so that certain things had to be documented. However, she then said that even if such a mechanism were in place some nurses would "do it" all the time, some "wouldn't do

any of it", and the remainder would fall somewhere in between. She seemed to say that no matter what, the physical care needs of the patient would be the priority. She ended on a positive note by suggesting that "how patients were feeling" could be recorded on the flow sheet. Flow sheets are always filled in. Accountability for providing emotional care to patients was an issue along with the belief that physical care of the patient would always be the priority. Family members were essentially not approached unless they initiated interaction or caused problems.

In summary, properties or attributes that were viewed as critical aspects of emotional supportive nursing care by patients included listening, understanding, and having empathy. Family members also seemed to value the provision of 'interactional' emotional support by the nurse. Interactions were characterised as being positive and cheerful. Family members linked providing information with giving emotional support. From the perspective of patients, the conditions that precipitated nurses giving emotional support included seeing that as part of their job—not just giving physical/technical care. Emotional support was seen as just as important as physical/technical care. In addition, having time, not being busy with other work due to health care economic cutbacks, and being held accountable through documentation in nursing records were cited as conditions that influenced the valuing and giving of emotional supportive nursing care. Family members indicated that they initiated contact with nurses. Nurses said that unless families approached them they assumed there were no problems. Nurses emphasised that the physical or technical care of the patient was the priority although providing physical, emotional,

and informational care seemed to be linked which will be explored further in the next section of this paper.

Linking Informational, Emotional, and Physical Supportive Nursing Care

In this next section, I will illustrate how informational care and emotional and physical /technical care were linked in the data. The properties, conditions and consequences of supportive nursing care that were drawn from the interview data will be presented.

Mrs. Moore and Family

Mrs. Moore was one of the two patients from the cardiac rehabilitation programme. She had been home from her six month hospital stay for approximately 12 weeks when I interviewed her. How she came to be in the study is relevant because I had initially been told about her by the nurses when she was hospitalised in ICU. During some of the time that she was in ICU she had a tracheostomy and was unable to be interviewed. So, I waited to interview her until she was transferred to the floor. On three different occasions I went to the floor to determine whether or not she was well enough to participate in my study but on each occasion she was still far too ill. She finally became a participant some 12 weeks later, through the cardiac rehabilitation programme. I was able to interview a nurse who had cared for her during her stay in intensive care and a nurse who cared for her in the cardiac rehabilitation programme.

Mrs. Moore had little memory of events that occurred while she was hospitalised in ICU or even on the floor. She said her family knew much more about

that time than she did. Her most vivid memory of that time which continued to haunt her dreams six months later related to having a tracheostomy, being suctioned, and being unable to talk while she was a patient in ICU. There was a remarkable fit between her nightmares of her tracheostomy and being suctioned and descriptions of that situation offered by the ICU nurse.

Since Mrs. Moore had little memory of the time she spent in ICU, her description of supportive nursing care centred on her experience at the cardiac rehabilitation programme. Mrs. Moore identified a nurse in the rehabilitation programme as supportive. Since her husband and daughter had such vivid memories of the ICU experience and since the ICU nurse had alerted me to the existence of this patient and her family, I also interviewed the ICU nurse. Mrs. Moore's description of supportive nursing care will be discussed first, then the cardiac rehabilitation nurse's description, succeeded by family members' and the ICU nurse's descriptions of supportive nursing care.

Mrs..Moore And the nurses are they're really great, you know. Um because I, I was having so much trouble when I first went (*to cardiac rehab*). And um, and it would really be easy just to give up. And I wanted to, you know. Because you just get so tired of plodding along, you know. But um, they're very good. I was having all this trouble with not being able to eat, you know. And one of the nurses (*named the nurse*) there, she referred me for the uh,....nutritional counselling. She made an appointment with the dietitian and uh, she (*the nurse*) had a lot of advice. And um, she helped me along that way. And that's and then, I saw her again, she was up there (*at cardiac rehab*). And um, you know she comes over and wants to know how I'm doing, which I thought was great. So, I'd say they just don't forget, you know. And they're very, the nurses up there really watch you closely.

Mrs. Moore referred to the cardiac rehabilitation nurses as being "really great" and again like many other patients and family members said the nurses were "good". However, she provided a specific example of how a particular nurse at cardiac rehabilitation had helped her. Here, in contrast to situations experienced by many

patients hospitalised on the floor, the nurse was seen as being able to do something of direct benefit to the patient. The nurse listened to her uncertainty, she made her feel she could improve her condition, she gave “helpful advice”, and she made a “referral” to an appropriate resource (the nutritionist). She was effective in coordinating care by quickly making connections to a helpful resource. The nurse did not need permission to make referrals. She just immediately followed through with helping to solve Mrs. Moore’s problem. Coordination of care was a condition of supportive nursing care that varied in effectiveness according to the health care setting. Nurses on the floor frequently had difficulty arranging connections with other health care professionals. Nurses often had particular difficulty in making arrangements for patients and their families to meet with their doctors. Beyond this practical assistance with a physical health problem, Mrs. Moore portrayed the nurse as knowing her as a person when she said “she (the nurse) wanted to know how I was doing” and “they (the nurses) don’t forget”. Finally, she ended her comments about supportive nursing with a statement uttered by so many other patients and family members in my study “the nurses watch you very closely”.

Mrs. Moore They have, the nurses are so good too. Because like the patients that are there....they’re not, like one lady in particular, she can’t have surgery, you know. And there’s been twice while I’ve been there, you know, where they’ve had to take her off the treadmill and um, you know and they really watch her close. And they’re right on. They just watch that monitor and they’re right there as soon as something goes ... astray. Yeah. And, and the cardiac rehab nurse said, don’t worry about it, she said. Cause I said, I won’t know if I can, if I go into congestive heart failure and she said, don’t worry about it. We monitor you three time a week. And so, I’m not gonna worry about it.

Being watched or monitored (Electro-cardiogram assessed continuously throughout activity) was a central concern for other patients and family members. In the above excerpt, there is the sense that the nurse’s behaviours of closely watching

the machines and making reassuring comments made Mrs. Moore feel safe and protected. Mrs. Moore lived with the uncertainty of not knowing whether or not physical activity would worsen her condition and with the unspoken uncertainty and fear of dying while doing physical activity.

Mrs. Moore's Cardiac Rehabilitation Nurse

The nurse identified by Mrs. Moore who gave her supportive nursing care was totally committed to the cardiac rehabilitation programme participants and their families. During the interview, she said she "loved" her job. Interestingly, this is a characteristic of supportive nursing care identified by Mr. Moore in my interview with him. This nurse was most interested in the study. She continued to talk with me for another 40 minutes after the formal interview had ended and recruited more participants to the study. Before working in cardiac rehabilitation, she had worked on a surgical floor and she said:

Mrs. Moore-N I think that, um, when you work in the hospital, it's all the physical, or that's all the time that you're allowed to spend with the patient, is with the physical aspects.

During my interview, this nurse described in detail how she valued family as an integral component of patient care. Her commitment to family care arose from her personal experience as a "cardiac kid". "Cardiac kid" is the label she applied to the children of cardiac patients. Her mother had experienced a heart attack and open-heart surgery at the age of 45 years and this 31 year old nurse indicated that this personal experience had influenced her to include family care in her nursing practice. During the interview, this nurse indicated that the cardiac rehabilitation programme had spousal group sessions and education days that encouraged the inclusion of

family members in the patient's care. The following excerpt illustrated the congruence between Mrs. Moore's representation of supportive nursing care and this nurse's representation.

Mrs. Moore-N Assessing her needs to see if she was a candidate for this programme. Because of the use of the walker and certain things, that um. But her initial contact was with concerns to diet and nutrition and someone had referred her to me because I teach a session on cardiac medications. She was having difficulty with her digestive system, relating to, I think now that I look back, it would be more with reference to side effects of combinations of drugs, not being one in particular. So, we sort of got that straightened out -- I got her latched onto nutrition counselling and with that I ended up spending more time with her, getting to know her a little bit better. Um, she has been through a lot. And, I think that, just to generalise, I think that the support that she needs is just, um to summarise it, related to the chronic illness. In general, I don't think that there's one particular area with Mrs. Moore. I think that it's just been everything for her, the weight loss, hair loss, medication, the accident, um the heart attack, failure. It's just been one thing after another. Um, I don't really know truthfully what her family support system is like. I know, she speaks very highly of her, her husband. She appears to be quite confident. But it's my experience that that may not necessarily be so. So, I, I don't really know. I've never met her husband. But from what she tells me, she seems to have some stability there at home.

The immediate similarity between the identification of needs described by Mrs. Moore with those portrayed by this nurse was striking. The nurse referred to Mrs. Moore as "she" in contrast to other nurses who used a generalised "they" during interviews concerning specific patients. Through the entire interview she consistently used "she" rather than the more impersonal, "they" perhaps denoting her individualised approach to supportive nursing care.

Although through the interview there were many references to the inclusion of family in care, the nurse was careful to say that she had not met Mr. Moore and that Mrs. Moore had attended daytime educational sessions alone. There was a valuing of the inclusion of family members in care and all patients were told when contacted about the programme that spouses were welcome to attend. Interaction occurred with family members when they approached the nurses. The family was accessed

through asking the patient how things were going at home. At three different times during the interview the nurse emphasised the importance of emotional care for the patient. In the following excerpt she described Mrs. Moore's progress and linked that to being more than "just a physical thing".

Mrs. Moore-N By the end of the eight weeks, um, she had started applying make up. She had started smiling and coming in and talking with the other participants and coming in earlier. I mean, the group dynamics that happen around here is just incredible. It's not just a physical thing. I think what's probably even a bigger part of it is that that person's sense of support comes from the group. And she was you know talking more to folks in her, in her class. It was just incredible. I think she is probably one participant over the last several years of my involvement with these type of patients that will always stick in my mind as far as progress, um, when you're looking at initial debilitation. She's now coming in and leaving doing 40 minutes or an hour at 5 mph (*on the treadmill*). When you think of progress in terms of large amounts, hers is in the quality. That to me, I think is a much greater feat. She's just, she's incredible. What we see on an EKG monitor is technically and legally a priority but when you think of it holistically, as a whole, it's secondary.

She acknowledged the "legal" importance of watching patients' EKG's, pulses, and heart rates but said it was "a secondary thing". She placed equal and even more emphasis on the "psychological support" for patients and family members and saw participation in exercise activities and group interaction with other programme participants as the vehicles through which patients "recovered" and got back to "normal" lives. She thought patients whose family members were involved in their care returned to "normal" more quickly. She depicted Mrs. Moore's progress as incredible because of the debilitated state that she had been in when she started the programme. Family was depicted as being context for patients. Families are included in the programme so that they can better understand the patient's illness and provide support to the patient. At the conclusion of the interview she summarised what she thought supportive nursing care was as follows:

Mrs. Moore-N I think it, um. Supportive nursing care with reference to cardiac rehabilitation is multi-disciplinary. Um, I think that we are the first, the forerunners with participants. They see us first. But then we refer them to the dietitians or the

diabetic counselling or we have even, you know, made contact with pastoral care and social services and this kind of thing. But um, yeah supportive care is supportive is the technical side of it because I think that is reassuring to know that when I hook them up that I see their EKG. I show them the papers and the numbers and the figures and the pressures more and more and then also the supportive care being the psychological issues the support issues with the family and also the patient. We talk about life-support with all the medical jargon and then the psychological life-support. Very interesting lots of fun. It's very rewarding and um participants leave here and they're ranting and raving, you did this, and I don't know what I would have done without you. But they don't realise that the support and the work comes from them and the group. We get them started and we sit back and we and it just happens the support, you know. They really are incredible—they support each other and they don't realise how healing it is to themselves to be supporting another participant. You see it all the time. A lady here, for example Mrs. Moore, she, she came in and she couldn't do very much at all and by the time she was leaving she was taking her transmitter, going into the ladies room, hooking herself up. She was hooking up the other ladies that were coming in that were new. I mean, pushing herself along and away she went. Now look at her, not much of a disability there at all. Incredible considering what she's been through. I think that I, because I don't know a lot about her family background, but because she has done so well, I assume that and maybe that's wrong on my behalf, that she has that kind of support at home. Because I think that in comparison to some patients that I know have more problems that they voice to me not having support at home. They don't seem to come along as well.

In describing what she thought supportive nursing care was this nurse immediately portrayed supportive nursing care as multi-disciplinary and cast the nurse in the role of coordinator of care. She also seemed to portray using technical or physical care information to give the patient a sense of being protected, reassured, and emotionally supported. The focus of the physical/technical care (EKG's, BP and pulse taking) was to provide the patient with a sense of being safe, of being emotionally protected or reassured. In the same way "numbers" were used to show progress to the patient and to provide emotional reassurance. The ability to pick up the phone and instantly make a referral was an activity that cast the nurse in the role of effective coordinator. Someone who had the power to make things happen for the patient's benefit almost immediately. There was a distinct contrast between the rehabilitation nurse's ability to "make connections" as compared to the floor nurse

whose repeated attempts to reach the doctor were neither observable by patients and family nor immediately effective. On the floor it took nurses several days to get the doctor to meet with the patient and her family. Mrs. Moore's rehabilitation nurse gave a precise, detailed account of Mrs. Moore's physical and psychological progress. She depicted Mrs. Moore's 'incredible' progress as being the result of Mrs. Moore's own ability to push herself (that internal strength or hardiness that her family and both nurses said she possessed) in combination with the "healing" that accompanied her ability to then help newcomers to the programme. She also suggested that patients whose families were not involved in their care 'didn't seem to come along as well'.

The Moore Family

I interviewed Mrs. Moore, Mr. Moore, and their daughter on an individual basis in the Moore family residence and returned one week later and interviewed the family as a whole. Each evening I arrived at 7:00 pm and did not leave until close to 11:00 pm. I attempted to leave earlier. However, the family were reluctant to let me leave even though interviews were completed. They were extremely interested in my study and eager to participate. The commitment and love they had for each other was obvious by the way they looked at and talked about each other. Mrs. Moore alluded to the strength of her family when she said, "I think when you've gone through, like having a son that's schizophrenic, if that doesn't tear a family apart, I don't think anything will".

Mr. Moore

Mr. Moore portrayed, for the most part a very positive picture of what he felt supportive nursing care had been for his wife. Excerpts from his individual interview are used to illustrate his view of supportive nursing care.

Mr. Moore Of course you're dealing at Hospital B, more the cardiac eh, and the nurses there are all very well trained there. It's gonna be a shame if they don't go in one unit to Hospital C. Because those girls there are all so well trained there that feel, you know. And in the critical care too. They made you uh, have no doubt about uh, you know that she wasn't getting the best services there was.

ER Um hum. Which made you feel?

Mr. Moore Yeah, made me feel better. Oh yeah, oh yeah! The nurses were were just great there. And I think even from the time she was in there they'd seen so many. I think there were certain nurses that had a better aptitude towards some things than others. Some were the more technical people and I think they were involved maybe at the start when she was on so many machines, it seemed.

The confidence he had in the care provided by his wife's nurses was grounded in his belief that they were "very well trained". The importance he attached to this "training" was evidenced by his repetition of the goodness of their training. This left him with no doubt that Mrs. Moore was getting the "best care". He then linked confidence in her care to his own sense of emotional security by saying that it made him feel better. He later quite clearly expressed his distress at the focus on "technical care" almost to the exclusion of emotional care.

Mr. Moore And then, maybe when she was off of those machines they had the other ones (nurses) who were maybe better caregivers or better morale boosters, or better that way.

Here, Mr. Moore clearly attached a great deal of emphasis on the "better caregiving" nurses as being those who were better at "boosting morale". I asked him to expand on what he meant by "a better caregiver".

ER So, when you—could you give me an example of what you mean by a better caregiver?

Mr. Moore Well, I think, uh when she was first on, when she was on so many machines and that. And you would go in and you would and you would ask the nurses certain questions. Well, they were, I guess they were so preoccupied maybe with that (*the machines*) equipment. She was very, very critical that they didn't um, they didn't talk that much

to you, you know. They give me all the answers and all that, but uhm. But then, when she come out and then she was on the other side, didn't seem maybe it was just on the other side of the hospital, you know. The side that the things (*machines*) on one side and and then when she got on the other side it kinda felt she was getting closer to the door. So she was gonna be a little bit better. And uh, the nurse, I never had, it never seemed that we had the nurse the same nurses that were over on the other side on this side. But that was perhaps just that they weren't trained enough, I guess. Maybe to be on those machines, you know. So, maybe I was wrong in saying what I did, you know. It's just that I suppose those nurses were trained to run those machines and the other ones probably weren't, eh. But, uh they were very helpful and you know when you phoned there they, they were very helpful, too.

He placed far more value on being "talked to" than being given information about how the machines worked or what was happening. He said the nurses were "preoccupied with the machines". The nurses gave him "all the answers" but they didn't "talk to him". There was a hint of the emotional dissonance he felt between being given answers but not really talked to. During the interview with the ICU nurse she spoke of feeling frustrated and torn between giving Mr. Moore emotional support and attending to the highly technical, complex care Mrs. Moore required. Mr. Moore used and emphasised "we" when he talked about the care the nurses gave. Did this mean he saw himself as part of his wife's illness or did it mean that he saw the nurse as providing care to both himself and to her? He spoke quickly and at length as he described the supportive nursing care he felt that the nurses gave.

Mr. Moore I just found those girls and the job they did was whether it was with the rehab or the ICU. They seemed to love their, doing their job and seemed to be very competent in it and and made you have confidence in them and uh, and they had a real good eh..... attitude and uh, cheerful and I think that's what a person wants to see in a nurse. When they go in there uh, you know somebody that, you don't wanta have somebody that when you go to visit somebody, somebody is down. They always were, were good. And uh, and uh accommodating. You know, I know there was some weekend there where she had trouble with her stomach. There was a nurse at the hospital.. and and she wasn't a young a real young nurse, but she went out of her way that weekend, I know, to try and help my wife there! She was having a lot of trouble with her stomach. I know she, she went like they say beyond the call of duty.

Mr. Moore linked nurses "loving their job" with being competent. He placed emphasis on the nurses' "attitude of being cheerful" which echoed the words of many

other study participants. He saw the nurses as “very competent”. He had confidence in their care which made him feel better. Competence, confidence, a positive or cheerful attitude, and being accommodating were intermingled and seemed to be attributes or properties of supportive nursing care.

Mrs. Moore’s Daughter

Mrs. Moore’s daughter was a 25 year old married woman living in her own household. She was a partner in a small business and had a very practical, no nonsense demeanour as she participated in the interview. She was very close to her mother and her father.

Mrs. Moore-D The nurses (*emphasis*) I find with uh, the intensive care, were EXCELLENT. There wasn’t a nurse that didn’t stand there and explain everything to her even though she didn’t know what they were telling her. Like I told my momma, they were always explaining exactly what was going on with her. And for them to say, like the night shift nurses, “call me any time”. They gave us direct numbers to the room like it was just excellent. We told them. Like you know once uh, things started getting a little bit better, for mom, we said, well, we still wanta restrict visitors. And they abided by it. Like you know, like, they had no problems with with doing that for us. Cause we had a few people that we didn’t think she was ready for yet. Like I found the ICU nurses were just excellent with that. Always keeping us informed as to what was going on. My dad could call at any given time and they’d give him updates. Which is excellent—I think they were all sad to see her go (*laughs*). Like, they had nurses going in there and doing her hair and her fingernails like you know. They just, they enjoyed her. And then when she was on the floor, they’d come visit her and she had nurses there that she remembered from the last time she was there on the floor. And like they were just wonderful! I says, well you’re good company, eh. So, that’s about all that really sticks in my mind with everything.

Mrs. Moore’s daughter said that the ICU nurses kept them informed about her mother’s condition and gave them information whenever they requested it so that they would know immediately if something was going wrong. Furthermore, the nurses listened to the requests that she and her father made and had the courtesy and power to enforce their wishes. The nurses seemed to meet the family need to protect the patient. In the next part of the interview, Mrs. Moore’s daughter clearly linked physical care, giving information to feelings of being emotionally supported.

ER Giving support to your mom at different points in time, if you think about what a nurse giving support to her in ICU what does that mean from your perspective?

Mrs. Moore-D I thought it was really good. Um, trying to boost her morale. And give her the lift that she needed and explain to her what was going on and stuff like that. Even though she didn't know what was going on. She didn't understand what they were saying to her, but that kind of. I was happy to see it. It kinda made me feel better. They're really doing a good job here! Yeah, very good. There were a couple there that were just excellent with her. Just excellent and really took a lot of time with her. But uh, from what I saw, I never had, I never saw a nurse at Hospital B that didn't give her that "okay let's go" "let's do it". "You can do it, come on". Like you know, don't just sit there and lie like a lump on a log. Let's get the the juices flowing, kind of thing. But uh, like they were excellent. Just excellent. I could never say enough (emphasised). Like, my dad will get a little huffy about things here and there. And I'm like (*whispered*) shush! Like, you know, they're doing a good job here. Like, they're short-staffed. Like come on, what do you expect, like you know. They are doing excellent for what they can. Cause they were always, always checking in on her, always. I'd go in and they're checking her tubes, and watch those fluids and stuff like that. They're always really good with her, always.

The classic comment "really good" made by so many patients and family members appeared in Mrs. Moore's daughter's response to my request to describe supportive nursing care. Similar to her father and the family members of other patients, Mrs. Moore's daughter placed great importance on the nurse being positive or "morale boosting" with her mother and seemed to portray that as being a way to reinforce Mrs. Moore's belief in herself and her ability to get well. She derived a great sense of emotional comfort or reassurance expressed as "I was happy to see that" and "I felt better" when she heard the nurses "explaining" everything to her mother. Even though she wasn't certain that her mother understood what they were saying, she "felt better". She clearly connected the act of information giving with emotional support and she did so several times during the interview. Again like the family members of other patients she said, the nurses were "busy" and suggested that nurses should not be blamed if care was not perfect. She implied that the nurses were "doing their best" under difficult circumstances. Even though they were "busy" they took a lot of time with her mother. Mrs. Moore's daughter's use of such phrases as

they were always “checking her tubes” and “watching those fluids” evoked images of vigilance and protection of the patient. In the more direct words of other study informants (for example the sons of Mrs. Pageau) “they kept her alive”. For Mrs. Moore’s daughter, emotional comfort seemed to be intermingled with physical care, and informational support.

Mrs. Moore’s ICU Nurse

Mrs. Moore’s ICU nurse had suggested to me that she thought that Mrs. Moore would be an excellent candidate for my study when Mrs. Moore was hospitalised in ICU. Mrs. Moore’s ICU nurse began the interview by telling me that she had cared for Mrs. Moore for two or three days in ICU when she was very ill. This nurse had encountered Mrs. Moore on the floor prior to her surgery and admission to the ICU. She described Mrs. Moore as an amazing woman who had been through a lot already and who was “very strong”. Mrs. Moore’s stay in the ICU had been filled with uncertainty. According to the ICU nurse and her family Mrs. Moore had been critically ill and came close to dying on several occasions during her six week stay in the ICU. There were many hurried family trips to the ICU in the middle of the night not knowing whether she would still be alive when they arrived.

Mrs. Moore’s ICU nurse portrayed Mr. Moore as a very emotional man who “found it very difficult to see his wife connected to anything”. She said he would come into the ICU room look at her, start crying, and have to leave. She described the daughter on the other hand as being someone who wanted to know everything

about her mother's treatment and care. She wanted to know what the machines did and what her blood pressure was and she wanted to help with her mother's care.

When I asked the nurse what kind of impact Mrs. Moore's illness had on the Moore family she said, "huge, I mean, I think that they thought they were going to lose her many times and she was the heart of that family". The nurse gave a detailed, individualised account of precisely how she gave Mr. Moore emotional support.

Mrs. Moore-N Emotional. Emotional, he was very emotional. Uhm, he was uh, I mean the few days, that I saw him. He got better, after the second day. Uhm, he responded well to the, to just simple things like, touch. And interaction and uh, if you, you know sat him beside the bed and let him, you know, I said, you can hold her hand. You can do anything you want, you know. TOUCH HER and uh, he responded well to that type of interaction. He wanted uh, he needed more uhm. I think the frustrating thing, for me was, he needed more emotional support than I could give him. Because she was so unstable, she was my priority and that was a frustrating part for me was that I knew he needed something but I couldn't give it. Because I was too, even when he would come in for visits, I was too busy with her. Because she was up and down like a toilet seat, you know. She was just everywhere. So um, I found his coping was very emotional. Very anxious and uh, worried and uh, tearful. Those, those types of things. Whereas his daughter was uhm, more information seeking, you know she wanted to know uh, what the heart rate was, did she still have arrhythmias, did this medicine work. Because I would you know, say, she's having a lot of extra heart beats. They're giving her a new medicine to see and then her daughter would want to know, you know. She would remember that and she would want to know. If it was working uh, she she asked more questions than her dad. He didn't ask any!

She indicated that Mr. Moore "responded well to touch" suggesting that she first determined whether or not this would be an appropriate approach with him. The nurse then gave him permission to touch his wife and assisted him in doing that since he was overwhelmed by all the technical equipment. Her approach seemed to work. Her awareness that "he needed more and I couldn't give it" is particularly notable because it fits with Mr. Moore's interview comments "the ones on the technical side, they answered my questions, but they didn't talk to me". The ICU nurse knew he needed more emotional support but could not give it. Tears slipped down her cheeks as she recalled her frustration at feeling she was not able to provide complete care for

both the patient and her husband. Other nurses raised this same issue and came to the same conclusion that the patient's physical care was the priority. On the other hand, this nurse was able to provide emotional support to Mrs. Moore's daughter. Her assessment of the daughter as an information seeker fit with data from the daughter's interview. The ICU nurse's "explanations of care" seemed to give emotional comfort to Mrs. Moore's daughter. Perhaps differences between this father and daughter denote the greater difficulty in providing him with the emotional support he seemed to need as opposed to that required by his daughter.

The following excerpt exemplifies the complexity and difficulty of providing emotional support in an ICU setting.

Mrs. Moore-N Uhm, that too was really difficult, because having to give them bad news all the time I found very stressful. You want to be able to tell them that they're doing well and that things are looking up and you want to be able to see some, give them some hope. Uhm, but I believe that you have to be honest with people and uhm I believe that you have a responsibility uh, to the patient to be honest with their family. That's what she would have wanted. She was a very, you know, from what I knew of her, a very straightforward woman. And um, wanted um, obviously had a close relationship with her family, so I wanted them to know. But uh, mainly it was the primary care nurse who was me for those first two or three days. I can't remember exactly how many days I looked after her. But, uhm no, I would have to have to say to the charge nurse, get the family, get them in here. I have to talk to them again. Uhm, and it just you know when they would come in, it was just, you know. She's not doing very well, right now, her blood pressure is quite low, we're having difficulty bringing it up. And you know, there's the chance that she might not pull through this (*voice soft and low*).

The ICU nurse depicted the dilemma of balancing her desire to give family members a sense of hope while at the same time feeling "responsible to be honest" about the possibility of her impending death. Delivering bad news was a very stressful experience for the nurse which she resolved by acting on her belief of being honest with people. Her belief outweighed the personal stress she experienced at always having to give bad news. The reader should know that when patients are

ventilated and in critical condition they are never left alone. The primary nurse may not leave the room and the critical nature of the patient's illness may at times require two nurses to meet the physical demands of care. That is the significance of her statement related to telling the charge nurse to "get the family in here".

Mrs. Moore-N And I wanted them to understand that we were doing everything we could but that the chance was there that it would not turn out. Uhm to be positive for them and then once that was sort of on the table, was there anyone they wanted us to call? Was there a priest? Uhm, you know. Or, was there someone that they needed, uh to contact? Were there more family from out of town that needed to be contacted? In what way could we help? Um, because at that point in time, I mean any other nursing unit who wasn't terribly busy could have done a lot of phone calling for them. So. It was just finding support for them because I couldn't provide it. You know.

Giving information to the family about the patient's health status was done deliberately to help prepare them for the possibility of her death. Again, this nurse was honest but at the same time conveyed the need for a sense of hope—of being positive. Being positive was highly valued by this patient and family and an attribute of emotionally supportive nursing care cited repeatedly throughout the study by many patients and family members alike. The mix of reality and hope was and is a dilemma faced by nurses in giving emotional support to both patients and family members. This nurse recognised her inability to provide the full support that the Moore family needed. However, she had strategies to find additional support for them from religion, from other family members, or by having other nursing units do the phone calling if needed. The dilemma of being torn between caring for a very critically ill unstable patient and caring for that patient's loved ones was an unresolved issue that has implications for family nursing. The following excerpt summarises the dilemma experienced by this nurse.

Mrs. Moore-N I think uh, the difficult part was, I think the whole. The difficult part in that whole situation was knowing that the family needed more than we could give them, at that time. Because of her condition. Because I had to concentrate so much on the

physical part of her health that uh, the emotional aspect in the family seemed to take second, third, fourth spot all the time. Which was frustrating.

From the perspective of the ICU nurse, attributes of supportive nursing care included the acuity of Mrs. Moore's condition and the interactions that occurred between her and the ICU nurse. The only memory that Mrs. Moore had of the ICU, other than being pampered just before she was transferred to the floor, related to being suctioned which she relived in nightmares.

Mrs. Moore-N Well, she was that unstable. And uh, I mean, I felt, I felt for her. Because whenever, she would wake up and she did wake up, frequently wake up. She knew she was sick. She knew she was dreadfully sick and uh, but she would comfort you, and pat your hand, you know. Especially, when you had to suction her. That was the worst part. Because she was very uh, her airway was very reactive. And uh, she used to get very bronchospastic. And uh, and cough, cough, cough, cough. And then she'd have arrhythmias and I mean, it was just like a vicious circle. So, once you got her settled down you could always talk her down. You could always get her to breath slower and it was very easy to calm her down. And then she'd pat your hand. You know, and you'd and I'd apologise. I'm sorry I had to do that. You know, because it really would upset, physically upset her and emotionally obviously too. When you cough like that. But uh, she would be the one trying to comfort you which always brought me to tears. CAUSE I MEAN GOOD LORD, WOMAN, YOU KNOW. YOU'RE ON DEATH'S DOORSTEP. DON'T WORRY ABOUT ME. Uhm, you know. But, she could see that it was upsetting to me to have to do it. And I felt so bad for her because I knew she was anticipating the surgery would was gonna make her life so much better. And it really hadn't at that point. And in fact at that time we really didn't think she was gonna make it.

The nurse almost seemed guilty for having to cause such distress to the patient and yet the patient was described as "comforting" the nurse. The interaction of "talking down" or calming of the patient during procedures was also described by other patients and family members. Explaining was something that other patients and families said that many nurses do very well and that resulted in feelings of being emotionally comforted in patients and family members alike. Explaining gave patients and family members a feeling of being secure in the knowledge that the nurse knew what she was doing and the explanations also bridged the gap between the medical world and their own ordinary world.

In my final interview question I asked this nurse to summarise what she thought supportive nursing care was for Mrs. Moore and for her family.

Mrs. Moore-N Um, supportive care for her? Um, I think what I did that was supportive to her was to inform her um of how, of everything that I did and um to make her as comfortable as I could. Uhm, I think comfort was the biggest supportive measure that I used with her. Because I knew, that I couldn't turn her the way I wanted to every two hours, because she was too unstable. So, it was a matter of uh, uh comfort things like, I must have done mouth care a thousand times on that woman. You know, on that one shift, because I thought it was the only thing I could do, you know. So I uhm, and I knew, I knew her mouth was sore. Because she had been intubated for a few days at that point, so I knew her mouth was sore. So, I made sure that, for me that was a comfort thing that I did for her. And emotional comfort. I made sure that I talked to her, told her that her husband had been in and that he was very concerned about her, uhm and even if he didn't stay it was, it was too hard for him. And, and she understood that, she would pat my hand. And I knew that that meant she, she understood. She knows him and so I think uh, I gave, I tried to give her as much emotional support as I could by giving her information about what day it was, where she was, uh, you know reminding her of who I was and uhm what I was about to do. For the family, supportive care uhm there was giving of information which I don't think was very supportive for the husband but for him I think supportive care was basically just letting him be uhm, letting him be upset. And letting him know that that was okay. To be upset. When I was there. He didn't have to leave. And I, and I think, finally what I said to him you know, was you don't have to leave. It's okay to be upset. She's your wife and I know you love her and I know she's important to you and if you want to stay that's fine, like I don't care how long you stay. I'm not one of those people who enforces the visiting rule. I, I, I you know. I could have them sit there for 12 hours I don't care. Um so, I think for him it was more, there was emotional support there was some information giving, and then there was the point where I just had him let him be himself and almost suffer on his own. Um, because I didn't know how to help him, at that point. I didn't know what he needed. And for the daughter, it was basically keeping her informed of her mother's condition and I think that biggest thing I probably did was I let them be in the room as much as possible. I, I don't have difficulty with that. So, for me that was the supportive thing that I did with just let them be there with her. I thought, if she's going to die. I want them to be in here with her. When it happens. And uh, or if it looks like it, which it did many, many times—look like it was going to happen. I want them to know that uh, they can be here. Uh, so I guess, for me that was what I did, that I felt was supportive as well as um, you know making sure that everybody had been informed if they needed people to be contacted and that type of thing. They didn't accept much help in that area. But, uh, it was offered.

The consequence of supportive nursing care for Mrs. Moore from the perspective of this nurse was the provision of comfort. She gave emotional comfort through informing, through physical care, through recognising the communication strategies used by the intubated Mrs. Moore, and through telling Mrs. Moore about her husband. She integrated physical/technical care, information, and emotional

support. She recognised the dilemma between the priority of physical technical care needed by the patient with the emotional needs of family members. She developed strategies to meet the informational and hence emotional needs of the family by coordinating meetings with the physicians. The most supportive thing she felt that she did for the family was "I let them be there with her". In ICU there is a policy for critically ill patients to only have visitors for five minutes per hour. This visiting policy is outdated and no longer based on research findings, however, it is enforced by some nurses. This nurse recognised the real possibility of death, gave that information to the family, and gave them the choice of being there with Mrs. Moore because she wanted them to know that this option was available to them.

Summary

Giving informational care and emotional support and physical/technical care were categories that emerged from the interviews on the topic of supportive nursing care. As the interviews progressed it became apparent that these categories were linked or intertwined in the words of patients, family members, and nurses.

Giving information involved subcategories of explaining and knowing and information was characterised by properties of clarity, accuracy, and honesty. Conditions that led to information giving included the patient and/or family asking, the nurse having time, the nurse valuing the activity, and the nurse not being too busy with other work. Being too busy could have been the result of recent reductions in the hospital budgets of the Ontario health care system. These budgetary reductions have caused the workloads of nurses to be increased. Patients derived a sense of

personal control from receiving information and family members found the information to be useful. When information was not provided or not understood then confusion and family conflict occurred.

Giving emotional support and physical/technical care was a major category of supportive nursing care. Physical/technical care of the patient surfaced as a priority for family members and nurses. However, further analysis revealed that patients, family members, and nurses often viewed physical care as being combined with the giving of emotional support. Properties or attributes that were critical aspects of emotional supportive nursing care for patients included the nurse listening, understanding, being interested in the patients' pain or worries, and having empathy. For family members, the main property was that the nurse interacted with patients and family members. These interactions were characterised as being positive, cheerful, hopeful, honest, and accommodating (allowing family members to be there, notifying family of changes, respecting family requests). One condition from the patients' perspective that precipitated emotional supportive care was that nurses had the time to provide this care. Another condition was that nurses gave patients permission to say what was on their minds. From the perspective of nurses, conditions included having the time (influenced by the acuity of the patient's health status), valuing the activity, and being held accountable for care (documentation in nursing records). The consequence of emotional support for the patients was a sense of relaxation. The consequence for families was a sense of confidence in the nurse because she boosted patient morale. Boosting of morale seemed to reinforce both patient and family strength or hardiness.

Supportive nursing care was characterised by the integration of informational, emotional, and physical/technical care for patients and their family members.

Conditions that precipitated supportive care included:

- the nurse valuing such care
- the institution endorsing such care (documentation)
- the nurse using technical/physical (monitoring EKG's and so on) and informational care to provide emotional support
- the setting (ICU, cardiac rehabilitation, floor)
- the nurse effectively coordinating care by getting answers for them from other health care professionals (doctors, nutritionist)
- the nurse loving her job

The consequence of supportive nursing care was the creation of a healing or therapeutic environment in which patients felt safe and family members and patients felt reassured and comforted.

ICU nurses identified feeling torn between providing care to critically ill patients and attending to the emotional and informational needs of family members. The patient was the priority but the dilemma of forced choice was frustrating to ICU nurses. For some nurses physical care was the priority while for others physical care was inextricably interlinked with giving emotional support and giving information to the patient and to the family. All nurses who were identified by patients and families as supportive gave all three kinds of care although some nurses may not have valued informational and emotional care as much as physical care.

CHAPTER 9

DISCUSSION AND CONCLUSIONS

In this chapter, I will begin by briefly reviewing the background for this study as described in the literature review. Making explicit the approach to reflexivity is important in a study such as this, and a particular case that arose during the course of data collection can be used as illustration. The first substantive part of the discussion chapter concerns family nursing theory. Then the discussion moves to elaborate on uncertainty, family responsibility, supportive nursing care and the course of chronic illness. Uncertainty and family responsibility emerged from the patient and family interview data. Whereas supportive nursing care was a collective definition derived from the responses of patients, their families, and nurses to a question about what supportive nursing care meant to them. I will discuss some issues that arose during the study in relation to the development of family nursing theory and draw conclusions about supportive nursing care, chronic illness, and family nursing grounded in the patient, family, and nurse interview data. Finally, I will delineate implications for practice, education, and future research.

Illness Context: Chronic Heart Failure

Since supportive nursing care in this study is situated in the context of chronic heart failure, a brief review of the main points and trends of this devastating illness is provided. Chronic heart failure is increasingly a sequel of ischemic and other heart diseases and is the leading cardiovascular diagnosis for hospitalisation and readmission. The increased survival of heart disease patients combined with aging of

the “baby boomers” is expected to result in ongoing acceleration in the incidence of this condition. Little is known about how heart failure patients and their families deal with this illness either in a life-threatening situation or on a day to day basis. As detailed in the literature review (Chapter 2), chronic heart failure is an illness characterised by enormous functional losses and has a physical, a psychological and a social impact on the patient and family.

My interest in these patients and their families grew from personal and practice experiences and earlier research work (Rukholm, et al. 1991). As a result of these experiences, I developed an acute awareness that a gap in knowledge existed concerning the kind of supportive nursing care chronic heart failure patients and their families wanted from nurses. There was also a gap in knowledge about the kind of supportive nursing care nurses thought they gave to heart failure patients and their families. Further, I wondered if a theoretical understanding of supportive nursing care could be grounded in their collective perceptions.

Little has been done to define supportive nursing care theoretically from the perspective of chronic heart failure patients, their families, and their nurses. Therefore, the purpose of the study was to gain knowledge that would advance understanding of supportive nursing care. Furthermore, it was proposed that the knowledge attained would contribute to a family-derived theoretical basis for family nursing. The original aim of this study was to explore patient, family, and nurse perceptions of the supportive nursing care that nurses provided to patients and their families during an acute episode of chronic heart failure and on a day to day basis.

Chronic Illness and the Family

Chronic illness and family research were the conceptual threads derived from the literature review that informed the underlying structure for the research approach. Chronic illness was defined as described by Strauss, et al. (1984) and Thomas (1984) and has been detailed in the literature review (Chapter 2). As discussed in Chapter 3, aspects of managing chronic illness as described by Strauss and colleagues (1984) were combined with elements from the work of Wright and Leahey (1984, 1987, 1994) to inform the interview schedule of this study.

For the purposes of this study, the family unit was central to the care of the chronically ill patient. There was an understanding that the family unit would provide such functions as caregiving during both acute exacerbation and during the non-acute phases of illness. As described in the literature review, the family is seen as more than context for the ill patient, it is also a system comprised of individuals in interaction with each other and with the surrounding environment (Friedemann, 1989). The study definition of family was derived from the Gilgun, et al. (1992) definition of family and further elucidated by Stuart (Chapter 2).

Bell and Wright (1990) defined the family as 'who the client says it is' whereas Wright and Leahey (1994) defined the family as 'who they say they are'. In this study, the patient was the entry to the family. The patient was approached and asked to participate in the study. Then the patient was asked to identify family members who were invited to participate in the study.

The Study

The main data gathering strategy used in this study was individual in-depth interviews conducted with patients, two family members, and their nurses. Patients

were interviewed either during hospitalisation (seven patients) or upon entering a cardiac rehabilitation program (four patients). Patients and their families were also interviewed as a group at their home no later than six weeks after being discharged from the hospital or shortly after beginning a cardiac rehabilitation program. In total, 11 patients, 11 primary caregivers, 9 other family members, 8 families as a group, and 11 nurses were interviewed. Four of the 11 patients were able to identify a particular nurse who they felt provided supportive nursing care. Seven patients were unable to identify a particular nurse who provided supportive nursing care.

When patients were unable to identify a supportive nurse, the nurses who provided nursing care to patients on the day that patients were admitted to the study were interviewed. Patients and family members gave reasons for not being able to identify a supportive nurse such as, being unable to single out a particular nurse because all the nurses were “good”. One of these patients was in ICU, one was in the rehabilitation program, and the remaining patients were on the floor. Other patients said that a nurse in ICU was supportive because she kept them alive. However, they could not remember the ICU nurse’s name when I interviewed them after they had been transferred to the floor. Consequently, I was unable to accurately determine who these nurses were. Three patients and their family members could not identify a nurse who was supportive and instead gave accounts of nurses who they felt were not supportive which helped inadvertently to indicate their perceptions of supportive nursing care.

The data generated from the interviews were used for comparative purposes. Interviews and interpretation of the data were based on the principles of grounded theory method. The study protocol was designed to develop a grounded theory from

the participant accounts. Textual data were analysed using constant comparative analysis.

Reflexivity

Making explicit the approach to meeting the canons of reflexivity is important in a study such as this, in particular to account for decisions made about the role of the researcher vis-à-vis information giving in the course of data collection. The particular situation that arose during data collection with the Roy family (Chapter 8) can be used as illustration.

In Chapter 3, it was suggested that reflexive accounting involves careful delineation of interactions among context, researcher, methods, setting, and informants (Altheide & Johnson, 1994) and further that reflexive accounting is one way of validating the research process in a qualitative, interpretative study. Reflexivity has been defined as "a self-awareness and an awareness of the relationship between the investigator and the research environment" (Lamb & Huttlinger, 1989, p. 766). According to Marcus (1994) there are several types of reflexivity all of which involve self critique. Reflexivity may serve different functions such as self critique of the experience and empathy evoked in the research environment; and self critique of the researcher's stance on the objectivity/subjectivity issue. The epistemological beliefs of the researcher tend to determine the subjective or objective stance taken by the researcher.

Objectivity is one of the tenets in traditional, quantitative research and means that researchers deliberately try to take a neutral stance on the issues under

investigation and distance themselves from subjects in order to avoid 'contaminating' the data. The assumption is that by doing so they achieve the goal of obtaining objective knowledge, free from bias. In contrast, qualitative researchers seek an interpretive understanding of human behaviour rather than searching for explanation, prediction and control (Holloway & Wheeler, 1998). In qualitative research the researcher uses "self as a research tool and use of self can help the researcher empathise and establish relationships with study participants" (Hutchinson & Wilson, 1994, p. 98). Reality is socially constructed and the subjective perspectives of the researcher and participants become integral to the data. The researcher is a part of the world that he/she studies and both affects and is affected by it. There is a "sense in which all social research involves participating in the social world, in whatever role, and involves reflecting on the products of that participation" (Hammersley & Atkinson, 1995, p. 16). The description of any decisions made in the case of data collection means that readers and reviewers, as well as other researchers are made aware of the subjective ideas of the researcher. Debates on objectivity and subjectivity in research shed light on the notion that there is no such thing as a single reality or truth but that multiple truths exist (Holloway & Wheeler, 1998).

Positivists would hold that any intervention such as, giving information would influence the relationship between the researcher and the researched and thus alter the outcome of the study. In other words, positivists would contend that any intervention would diminish objectivity and hence contaminate the process and findings of the study. Hammersley and Atkinson (1995) state that "what both positivism and naturalism fail to take into account is the fact that social researchers are part of the social world they study. The distinction between science and common sense, between

the activities and knowledge of the researcher and those being researched, lies at the heart of both these positions” (p.16).

Responding to participants’ requests for information could be seen as posing a threat to the credibility of the process and findings depending upon the epistemological view held by the researcher. If the purpose of the study, as in this case, is to explore perceptions of supportive nursing care then does responding to participants’ requests for information taint the data and threaten the truth value of the findings? Will relationships between the researcher and the participant be affected and will informant views of supportive nursing care be affected and hence render the quality and credibility of findings questionable? The position adopted in this study was based on the notion that the interview constitutes a dialogue between the researcher and the informant and that legitimate knowledge is derived from that dialogue. Such dialogue may involve intervention on the part of the researcher (Anderson, 1991; Hammersley & Atkinson, 1995; Marcus, 1994). Thus, giving information in the context of this study can legitimately be interpreted as germane to the research and importantly, as providing opportunities for the researcher to establish trust and rapport with the study informant (Hutchinson & Wilson, 1994) and to generate knowledge relevant to the study. Robinson and Thorne (1988) suggest that one way of handling issues related to reflexivity, and in particular to intervention, is to have ongoing involvement and advice of advisors at all stages of the research. The issue of intervention was discussed at length with my supervisors.

The case of the Roy family can be taken to provide illustration (Chapter 8). This was a case in which I intervened by providing information regarding palliative care assistance. This intervention may have influenced my relationship with Mrs.

Roy's daughter and may have influenced the decision by the Roy family to maintain Mrs. Roy in her granny flat. It is not possible to say for sure whether my intervention influenced the decisions taken in this family concerning Mrs. Roy's living arrangements in the long term. However, I believe my actions were appropriate in the circumstances and did create a sense of trust and rapport between Mrs. Roy's daughter and myself.

For research interviews to be effective, the two parties must establish rapport. Good interviewers must "be present" in the situation, attentive, and responsive to the verbal and non-verbal communication of the participant according to Hutchinson and Wilson (1994). In responding to Mrs. Roy's daughter's expressed need for information, I was attempting to be attentive and responsive to the verbal and non-verbal communication of the participant.

My actions may well have positively influenced the relationship between Mrs. Roy's daughter and myself and may have made her more open to disclosing information to me. The converse could also be true: after disclosing family conflict she may have reflected on the interview after I left and regretted divulging so much personal information to me. It is difficult to know. On balance, the positive interpretation is the more credible since it is the case that I was welcomed at the subsequent interviews and at the final family interview.

Ultimately, the purpose of reflexivity within the qualitative interpretative paradigm is to enhance the credibility of the research findings. Reflexivity involved delineation of my position on the subjectivity/objectivity issue, laying bare the epistemological beliefs that underscored the decision making process, and ongoing discussion of the issue of intervention with my supervisors. It is for the reader then to

then judgements about the authenticity and goodness of my findings.

Contribution to Family Nursing Theory

The generation of new knowledge for nursing practice can be accomplished through research and theory development. The link between nursing practice, research, and theory has long been acknowledged and accepted in the world of nursing academics (Dickoff, et. al, 1968). Meleis (1997) suggested that for the discipline of nursing, knowledge could be generated from the interplay between theory, practice, philosophy, history, research, and science. The interplay between theory, practice, and research was of particular relevance to this study. Research grounded in nursing practice is key to the development of theory which can then be tested and applied in practice. Grounded theory comes from practice with the ultimate intent of being used in practice.

Articulation of the properties, conditions, and consequences of the concepts that emerged from this data is congruent with the development of descriptive theory as described by Meleis (1997), "descriptive theories describe a phenomenon, speculate on why a phenomenon occurs, and describe the consequences of the phenomenon" (p.18). Furthermore, in keeping with the belief that nursing knowledge is public, Gortner (1990) appealed to nurse researchers "to identify and specify the conditions under which the concept or phenomenon is found. These conditions represent the linkages of the abstraction with reality, increasing the likelihood that the abstraction may be found again" (p.61). I have attempted to contribute to nursing knowledge by extending understanding of family responsibility and supportive nursing care for patients and their families as concepts that emerged for patients, families, and

nurses in the context of the uncertainty of chronic heart failure. Issues concerning family nursing theory arose during the conduct of the study and will be discussed relative to extending knowledge about family nursing theory. The properties, conditions, and consequences of uncertainty, family responsibility, and supportive nursing care will be delineated, followed by a discussion of how knowledge of these concepts has been developed relative to the current literature.

Defining the Family

An important consideration in the expansion of knowledge is the generalisation of findings. How the family is defined raises questions about the generalisation of findings. To whom can findings be legitimately generalised? In a paper presented at the University of Edinburgh (Rukholm, 1997), implications of the definition of family for the generalisation of research findings were discussed. In considering definitions of family a number of questions were explored. What is family? Can research concerning family generate theory when family is defined as who they say they are? Does such a definition open the door to a myriad of combinations and permutations and hence raise questions about the generalisation of findings? Can research findings be generalised if they are based on such an open-ended definition? Can findings of family nursing research be applied in practice if the families presented in the research are either not defined at all or not clearly defined and not positioned within a theoretical perspective?

There are many ways of defining family. The nuclear family, based on a relationship of love between husband and wife who have children and then live together in the same household, is the most commonly held view of what constitutes

family (Gelles, 1995). Scottish, Canadian, and United States Census data do not reflect this idealised view of the family. There is no one type of family and there is much argument and debate about just exactly what constitutes a family. In the context of family nursing research there is no correct or incorrect definition. Rather, the nurse should examine the fit of the definition of family with the research question asked, the philosophical world view held by the researcher, and the methodology that is used in the study. The definition of family used by the nurse researcher must be articulated so that readers can judge the utility and appropriateness of the findings of research based on that definition for their practice.

Family nursing research can be carried out when the family is defined as being 'who they say they are' (Wright & Leahey, 1994), and when the family is identified as 'who the client says it is' (Bell & Wright, 1990). Robb (1998) suggested that both definitions have utility for practice. Defining the family as who the client says it is allows the patient to define who their family is and use of such a definition is helpful because it includes non-traditional families. On the other hand, the definition of the family as who they say they are has relevance in practice when "the patient is very ill and unable to communicate with the nursing staff of the intensive care unit" (Robb, 1998, p. 118). The critical points in a research study are clear definition of the family and consistent application of that definition. Entry to the family in this study was through the patient therefore patients identified who they felt were family. Consistent application and 'visibility' of the definition has been provided so that the reader can make judgements concerning the applicability of findings to practice.

Family Nursing Theory

The definition of family nursing is as controversial as the definition of family itself. As discussed at length in the literature review (Chapter 2), various authors have classified family nursing into different levels of practice. According to Friedemann (1989), the concept of family nursing encompasses at least three levels including 'nursing of the system of individuals, the system of dyads, triads, and larger groups and the entire family system'. Other nurse researchers such as Gilliss (1989), Wright and Leahey (1994) have also identified levels of family nursing. Family nursing for Gilliss (1991) focuses on the family and the individual at the same time and could be likened to family systems nursing as described by Wright and Leahey (1994) and Friedemann's (1989) family system nursing. Each of these family nurse researchers acknowledged systems theory as a fundamental cornerstone of family nursing. I concur with Whyte's (1997) view that family nursing 'requires seeing the family as the unit of care and viewing family from a systemic approach' (p.5).

These classifications of levels of practice represent an attempt to differentiate kinds of family nursing. They reflect the ongoing struggle for theoretical clarification of family nursing. The contribution this study makes to the struggle for theoretical clarification centres on the simultaneous attention given to the individual and the family by the nurse seen in practice. The dilemma of providing care to both patient and family will be explored and some of the factors that influenced such care identified. Simultaneous attention to the individual and the family raises questions concerning how the concepts of family and family nursing fit with the nursing metaparadigm (Fawcett, 1984; Whall & Fawcett, 1991; Robinson, 1995).

Friedemann (1989) raised the problem of harmonising the concepts of family

and family nursing in relation to the metaparadigm. The metaparadigm refers to the global concepts of person, environment, health, and nursing described by Fawcett (1984) and others (Whall & Fawcett, 1991; Robinson, 1995) as the fundamental elements of the discipline of nursing. The question is, where do family and family nursing fit in the metaparadigm of nursing? If the concept person is viewed as plural then the concept person (unit of care) could represent the individual, the group, or the community. Indeed, Neuman's (1983, 1989) systems model conceptualised person as individual, family, or community. If family is conceived as being an aspect of the environment (context that has an impact on the person's health), then family becomes the context for patient care. On the other hand, family could be considered simultaneously as an aspect of the concept of person (unit of care) and the concept of environment (context). Friedemann contends that the family needs to be understood as part of both ie. the concepts of person and of environment, or that the nursing metaparadigm be expanded to include two more concepts: family, and family nursing. I argue that family and family nursing is part of the larger nursing metaparadigm. Data from this study support a dynamic view of the metaparadigm in which person is conceptualised as part of a family system yet the integrity of person as individual is maintained. Such a conceptualisation allows the nurse to focus in some situations on the family as context for patient care and in other situations on the family as the unit of care, or both.

Robb (1998) suggested that the focus of family nursing shifts between the individual and the family system. Fluctuation in the focus of care has led to the depiction of family nursing as a continuum with the individual in the context of the family at one extreme and the family as unit at the other (Craft & Willadsen, 1992).

The data from this study challenge the conceptualisation of family nursing as a continuum since analysis of the data revealed that attending to patient and family needs occurred simultaneously. However, as illustrated in a subsequent section of this discussion, providing such care can prove to be a dilemma for the nurse.

Wright and Leahey (1994) and Friedemann (1989) hypothesised that the level of family nursing (family as context, family as unit of care, or both) may be a function of the context of nursing care (ICU or rehabilitation setting) and the competency of the nurse. In this study, fluctuation between caring for the patient in the context of the family and caring for the family as a unit was also affected by the acuity of the patient's illness and variance in the kind and the amount of support required by individual family members.

Difficulties encountered by an ICU nurse in simultaneously delivering patient and family care will now be explained. Explanations were grounded in the data and will be compared to the current literature to illustrate how variation in the kind and amount of support required by family members, acuity of the patient's illness, competency of the nurse, and setting influenced family care.

The Dilemma: Choosing between the Patient and Family

From the perspective of an intensive care unit nurse, the dilemma of feeling forced to choose between the patient and family as the focus of care arose as an issue and has implications for family nursing theory. One intensive care nurse (Chapter 8, Mrs. Moore's nurse) expressed a great deal of distress and frustration over the quandary of wanting to care simultaneously for both the patient and the family. Other ICU nurses expressed similar concerns. Mrs. Moore's ICU nurse felt torn

between caring for the patient and caring for the family in the face of life-threatening needs of the patient. She emphasised the critical nature of the patient's condition when she said that two nurses were required to meet the highly technical, physical demands of patient care.

The critical nature of the patient's health status made technical and physical care of the patient the priority. Chavez and Faber (1987) suggested that the primary focus of care in the intensive care unit is the patient. Turnock (1989) suggested that the acuity of the ICU patient and the complexity of technical equipment makes the patient the primary focus of care. Yet, the nurse in this study felt compelled to also address the informational and emotional needs of the family. The nurse acknowledged that the patient was the priority. However, she deliberately attempted to meet the emotional and informational support needs of the family while simultaneously acting on the physical/technical care needs of the patient which were a priority.

This patient was on a ventilator, unable to communicate and apparently unaware of the presence of others. Yet, the nurse brought the family into the patient's environment in order to meet their needs rather than to meet the needs of the patient. This demonstrates well the reality in practice of the family unit and not only the individual patient, as the focus of nursing. The individual patient is nested in the family system. Family assessment skills enable the nurse to discern the relative importance of the family system for each patient.

Complexity of care affects family care. The combined complexity of care required by the patient and the family may affect the delivery of family nursing. The nurse's frustration arose from feeling she could not provide the extent of emotional

support needed by a family member and simultaneously attend to the multiple technical aspects of care of a highly unstable, critically ill patient. However, she was able to meet the informational needs of another family member who coped through seeking information and participating in the patient's physical care. Perhaps the demands on the nurse of providing emotional support to family members exceed those of informational support in situations where the patient is critically ill.

Acuity of the patient's illness affects family care. The focus of care was a dilemma for the ICU nurse when the acuity of the patient's illness required her entire attention and hindered her ability to fully address the emotional needs of a family member. However, despite her frustration at feeling she could not fully meet the family emotional demands and simultaneously address the care for the critically ill patient, she did not exclude family from being with the critically ill patient. Clearly, focusing on the patient does not preclude simultaneously using strategies to meet family needs nor should the critical nature of the patient's health status result in excluding family during crises when the patient's life is in the balance. The nurse used and suggested a number of strategies to meet both family member and patient needs. When the patient's survival was a concern, this nurse reacted by wanting the family to be there with the patient. She did not exclude family when the patient's life was at risk although the demands of patient care were a priority.

Competence of the nurse may influence family care. The competence or knowledge and skill of the nurse may influence the delivery of family nursing. Inclusion of family in the intensive care patient's room during life-threatening situations raises questions concerning how decisions are made about when and who in the family should be present. Visiting in the intensive care unit has been the subject of

debate in practice and has received some attention in the research literature (Boykoff, 1986; Hickey & Lewandowski, 1988). On the basis of her personal feelings and knowledge of current research, this nurse contended that if family wanted to be present they should be present. Leske (1991) called this need of family members to be present 'proximity needs', which she defined as 'reflecting the quality of being near or close, both physically and emotionally'. Robb (1997) suggested that it is essential for the nurse to provide physical and emotional care but that it may be equally important for the patient to receive reassurance and support from family members. The ICU nurse in this study further acknowledged that inclusion of family meant that they needed to be prepared so they could interact with the patient in a way that was meaningful for them. This latter point is reiterated by Robb (1997) who felt that the family should be 'enabled to come to its own decision' about how and when family presence and participation in care occurs. Flexible visiting and attention to proximity needs may be beneficial for the patient and family even in life-threatening situations. Study data suggested that the competence or level of knowledge and skill of the nurse influenced her ability to deliver family care.

The preceding discussion of the dilemma faced by this ICU nurse was based predominantly on the analysis of the data pertaining to Mrs. Moore and her family and can be found in Chapter 8. The ICU nurse had worked in an intensive care unit for 10 years and was educated at the Master's degree level, specialising in cardiovascular nursing with an emphasis on family care. For descriptions of the attributes of other nurses in this study, see Table 2, Appendix A.

Setting may influence family care. The setting of nursing care may well influence the level of family nursing (family as context, family as unit of care, or both).

In the cardiac rehabilitation setting, similar to the intensive care setting, physical safety of the chronic heart failure patient was a priority. Traditionally, chronic heart failure patients have been excluded from rehabilitation programs because their severely reduced left ventricular function makes them particularly susceptible to life-threatening cardiac events during exercise (Sullivan, 1994). These patients continue to be vulnerable to cardiac events during exercise, however, the benefits of exercise training are now thought to outweigh the risks. Nevertheless, such patients are at risk for life-threatening cardiac events and require close supervision and monitoring while participating in the exercise rehabilitation program. Accordingly, the nurse closely monitors electrocardiograms and blood pressures during physical activity. Despite the potential for life-threatening events, the focus of care in the rehabilitation setting is on recovery for both patients and their families. The demands of physical/technical care are present but they are not as complex or as diverse as in the intensive care setting and rarely put the nurse into the dilemma of having to choose between the patient and family as focus of care.

In the cardiac rehabilitation programme, family study participants were routinely invited to observe patient exercise sessions and one-on-one counselling was given to patients and to family members on a formal and informal basis. In addition, there were groups combining patient/family education sessions and separate family sessions. The focus of care shifted from individual to family to both. According to the nursing metaparadigm this means that in the rehabilitation setting, the family can be 'person' (focus of care) or 'environment' (context for patient care) or both. However, in this study family as context tended to be dominant. Perhaps, family was the context for patient care rather than the focus of care because sessions occurred

primarily during the day when family members were at work. In addition, family was context for patient care because as the acuity of illness receded and improvements in patient stamina were seen, the threat of loss of a loved one receded. Study data indicated that both patients and family members expressed confidence in the rehabilitation nurse because they felt safe and secure in the knowledge that she was 'watching'.

In the rehabilitation setting, the focus of supportive nursing care for patients and their families from the perspective of the nurse was on the dissemination of needed information and the provision of emotional support combined with monitoring (watching) of cardiac functional status to create a healing environment. The nurse described the monitoring of vital signs such as blood pressure and electrocardiogram as distinct aspects of technical/physical care needed to identify potential cardiac events. However, she did not view this technical care as an isolated activity. Rather she connected technical care with giving the patient the emotional support of being reassured that exercise would be halted and cardiac events avoided should that prove necessary. Patient and family interview data revealed that they felt emotionally reassured by knowing that they were being monitored (Chapter 8, Mrs. Moore, Mrs. Levesque).

In both the intensive care and rehabilitation settings the interconnectedness of giving information with giving emotional support and technical care explained the family need to be assured that the patient was safe and receiving competent care. Therefore, family members felt comforted and reassured. Patients and family members articulated differences between nurses who gave such care and those who did not. There is no doubt that physical technical care was a priority in life-

threatening situations, however, the interconnectedness of giving information, providing emotional support, and giving physical technical care even in life-threatening situations was evident. I contend that these elements were inextricably intertwined in the eyes of patients and family members and that they may have contributed to the creation of a healing or therapeutic environment for patients and their families. In life-threatening situations, there was a difference between giving competent technical care and giving competent technical care along with needed information and emotional support to the family. The complexity of patient care and the type of demands of family care had an impact on the nurse's ability to provide integrated supportive nursing care. However, strategies were put in place to include family even at times when the patient's life was at risk. Many patients and family members said that nurses were very good at explaining equipment and giving information about what they were doing. They also asked for and valued emotional comfort. The congruence between patient, family, and nurse identification of supportive nursing care was striking. Supportive nursing care will be discussed in greater depth in a subsequent section of this discussion.

In summary, this study contributes to theoretical clarification of family nursing shedding some light on the dilemma of simultaneously providing patient and family care and explaining some of the factors that influenced such care. Specifically, the study data support a dynamic view of the nursing metaparadigm that includes family nursing by conceptualising 'person' as being part of the family system. This allows the nurse to focus in some situations on the family as context for patient care and in other situations on the family as the unit of care. I have further clarified and advanced knowledge of family nursing by showing that the delivery of family nursing may be a

function of the context of nursing care (ICU or rehabilitation setting) and the competency of the nurse. In addition, fluctuation between caring for the family as context for patient care and family as unit of care (patient and family receive simultaneous care) was explained by the acuity of the patient's illness and variance in the kind and the amount of support required by family members.

Family Nursing – Reciprocity and Interaction

Furthering understanding of reciprocity and interaction also contributes to the theoretical basis of family nursing. Family nursing that focuses simultaneously on the individual and the family as recipient of care is concerned with interaction between family members and reciprocity between the family and the illness and the illness and the family (Wright and Leahey, 1994). Friedemann (1989) hypothesised that for the nurse to provide care at the family systems level (family as unit of care) she must be able to understand the interactions between family members and the effect those interactions have on individual family members in relation to the family as a whole. Hanson (1987) further states that "Illness affects the family as a whole, and the family affects the individual's response to illness" (p. 7). Hence, Wright and Leahey (1994) have proposed that changes in the family system and the individual affect each other reciprocally. In other words, the family's reaction to the illness has an impact on the patient and the patient's illness has an impact on the family.

The concepts of uncertainty and family responsibility that emerged from the analysis of study data expand on the 'interaction' element of the family nursing definition proposed by Hanson (1987) and will be articulated in subsequent parts of this discussion.

The purpose of family nursing is to promote, maintain, and restore family health; it is concerned with the interactions between the family and society and among the family and individual family members. (Hanson, 1987, p.7)

The uncertainty of chronic cardiac illness was the core problem that resonated through the family. Family responsibility emerged as a response to the uncertainty of life threatening chronic illness and deteriorating health. The concept of family responsibility reflects the reciprocal relationship that occurred between the illness and the family, and the family and the illness and demonstrates the utility of systems theory as a foundation for family nursing. In family nursing at the 'systems' level "the relationship between the family dynamics and the health issue is assessed and seen as the focus of intervention" (Duhamel, 1995). As noted earlier, supportive nursing care as described by patients, their families, and nurses involved an integration of physical, emotional, and informational support. Each of these concepts—uncertainty, family responsibility, and supportive nursing care will be further developed in subsequent parts of the discussion. The next part of the discussion will address the uncertainty experienced by patients and their families and then show how these findings have advanced theoretical understanding of uncertainty with regard to family nursing theory.

UNCERTAINTY

In this part of the discussion, I will argue that both patients and their families experienced uncertainty and uncertainty has implications for nursing practice. Patients and families were uncertain about what symptoms meant, about whether or not to go to the hospital when symptoms occurred, and about what to expect in the

future.

Uncertainty occurred in relation to patients and families being unsure about the meaning of symptoms which was then linked to decision making about whether or not to go to the hospital when acute illness events occurred. Uncertainty was also evident regarding expectations about physical, social, and emotional activity levels, after discharge from the hospital. I will argue that uncertainty had particular properties, that conditions in the various players and in the surrounding environment contributed to uncertainty, and that uncertainty had consequences for patients and families.

Uncertainty was attributed in part to the unpredictable and ambiguous nature of the symptoms experienced. The properties of uncertainty included:

- the unanticipated, unexpected onset of symptoms
- the ambiguity of the meaning of symptoms
- the apprehension of feeling unwell and not knowing the cause
- the indecisiveness and confusion about the action to take
- the unpredictability of the future occurrence of symptoms
- the unpredictability of prognosis

Conditions that contributed to uncertainty involved characteristics of the illness. Specifically conditions included sudden deterioration of the patient's heart condition resulting in emergency hospitalisation, patient and family lack of knowledge or understanding of the meaning of symptoms and the action to take to deal with them, and phase of illness. As a consequence of uncertainty, family interactions occurred that were characterised by conflict, distress, agitation, fear, anxiety, and frustration. Patients and family members did not necessarily experience the same

feelings.

Being uncertain about the meaning of symptoms, trying home remedies to relieve symptoms, and hesitating to seek health care assistance are behaviors that occurred and that potentially jeopardise the lives of heart failure patients. Interactions between the family and the patient influenced the way uncertainties were handled. Early recognition of symptoms and taking appropriate action are critical to the effective management of heart failure. Armed with knowledge and the ability to detect symptoms of impending heart failure, patients and family members have the opportunity to make an informed decision about whether or not health care assistance is needed.

Uncertainty provoked a wide range of emotional responses within patients and their families. Patients and family members did not necessarily experience the same emotions. Such differences disrupted family relationships and ricocheted throughout the family. Nurses might well be able to help patients and their family members deal with these emotional differences and address the impact they may have on family relationships.

Patients and family members expressed uncertainty about what to expect in the future regarding physical activity levels, emotional and social activity, and the recurrence of symptoms. Such uncertainty resulted in anxiety for both the patients and family members and contributed to family conflict/confusion over what activities would or would not be harmful to the patients. The interplay that occurred between family members illustrated the reciprocal relationship between the ill member and the family and the family and the ill member.

Uncertainty about the future included questions about when and how death

would happen and was a concern expressed both by patients and family members. Questions about the amount of time until death tended to be either left unanswered or are answered in ambiguous ways. Cohen (1993) suggested that such ambiguity occurs possibly because medical personnel cannot give concrete predictions. In this study, concrete information provided by medical personnel pertained to the degree that the patient's heart condition had worsened rather than to a prediction about when death would occur (Mrs. Roy, Mr. Martin). Such statements about the deterioration of the patient's health led family members to construe that death would occur at a vague but somehow imminent time in the future. Such ambiguous information prompted families to feel responsible to take care of and protect the patient. For some families, the uncertain prognosis resulted in fear of being held responsible if anything happened to the patient, conflict between family members, and hasty decisions to move patients to an environment where they could be watched. Some patients talked openly about impending death, others did not. In some families initially there was closed awareness that death could happen at any time. In other families, there was open acknowledgement and discussion.

Extending Knowledge of Uncertainty and the Family

In grounded theory as the examination of the data becomes more focused and major categories emerge, a dialogue between the researcher, the literature, and the data is conducted. Having identified uncertainty as a major category, I searched the literature to determine how other researchers had approached this topic. I found that uncertainty had been addressed primarily as a psychological cognitive process (Mishel, 1981; Mishel, 1990). Although Mishel's theory had been used with patients

and family members, it is essentially a psychological or individual-focused theory. Thus, in contrast to this study, Mishel conceptualised uncertainty from an individual rather than a group interactive perspective. There was also controversy in the literature concerning the nature of the outcome of uncertainty as a sustained phenomenon in chronic illness (Mishel, 1990; Rolland, 1994). Knowledge gained from this study contributes an understanding of family interactions and reciprocity in the context of uncertainty, and further helps to clarify outcomes of sustained uncertainty for patients with chronic heart failure and their families.

Since the development of her theory of uncertainty in illness in which she postulated that the individual adapts to resolve uncertainty, Mishel's (1981) approach to the study of uncertainty has dominated the nursing research literature. A Medline search of the literature uncovered 39 studies of uncertainty, the majority having used Mishel's conceptualisation. Most of these studies focused on acutely ill individuals, some on chronically ill individuals, and a few studies examined patients and family members (Cohen, 1993; Turner, Tomlinson, & Harbaugh, 1990; Northouse, Dorris, & Charron-Moore, 1995; Baier, 1995; Northouse, Templin, Mood & Oberst, 1998; Malone, 1997; Germino, et al., 1998). Most of the studies that included family members did not examine interactions between family members or reciprocal relationships between the ill member and the family and the family and the ill member.

Five studies examined patients and their families in chronic illness situations. Cohen (1993), in a grounded theory study of children with a newly diagnosed, life-threatening, chronic illness, reported findings that explained parental behaviour of learning to manage life under conditions of sustained uncertainty. Similar to my work, Cohen reported that ambiguity of the illness led to changes in family activities

and relationships. However in contrast to this study, Cohen identified changes in the family in response to life-threatening chronic illness but not the impact of the family's response to the illness on the child. Findings from this study take the examination of uncertainty of chronic life-threatening illness one step further than Cohen by revealing the reciprocal impact of the patient's illness on the family and the family's response to the illness on the patient (Chapter 6, Mrs. Roy, Mrs. Moore, Mr. Peterson).

Wright and Leahey (1994) described reciprocity in the context of cybernetics. Cybernetics refers to the reciprocal communication that occurs between persons and has a circular pattern. This circular pattern of communication between two people results in each individual having an impact on the behaviour of the other. These circular patterns can have positive or negative consequences. A reciprocal communication pattern concerning uncertainty is illustrated by the example of Mr. and Mrs. Peterson (Chapter 6). Mr. Peterson expressed his confusion and concern about how much and what kind of activity he should have been doing after going home from the hospital. Mrs. Peterson responded by expressing her equal confusion and concern for him. Mrs. Peterson contacted their family physician and then the cardiologist in an attempt to get some clear directions for Mr. Peterson.

For families in this study, the uncertainties of chronic life-threatening heart failure triggered interactions that led to a feeling of family responsibility to take care of and protect the patient. Family responsibility resulted in enormous changes in the lives of both patients and families and is further explained in a subsequent section of this discussion.

Two studies by Northouse, Dorris, and Charron-Moore (1995) and Northouse, Templin, Mood, and Oberst (1998) reported a high degree of

correspondence between the levels of role adjustment reported by women with breast cancer and their husbands. These researchers recommended assisting couples, not just patients, to manage adjustment to breast cancer. Similar to Northouse, et al., study informants also experienced adjustments in response to the uncertainties of chronic illness. However, my work goes one step further by identifying that adjustments arose from interactions that occurred between family members and had both positive and negative consequences for patients and their families.

Malone (1997) studied patients with long-term physical or mental illness and their families and found few statistical differences between patients and family members on multiple assessments of family function. On the other hand, Baier (1995) applied Mishel's (1990) reconceptualisation of uncertainty to a qualitative study of patients with schizophrenia and their family members and found, similar to my findings, that uncertainty was manifested differently by patients and family members (Chapter 6). In their study of uncertainty in relation to family coping, psychological adjustment to illness and spiritual factors for prostate cancer patients and their families, Germino, et al. (1998) also found similarities and discrepancies between patient and family responses to uncertainty. The study findings suggest that difference in responses to the uncertainties experienced by patients and their families could be explained by the interactions that happen between patients and family members.

The nature of uncertainty as a sustained phenomenon in chronic illness has also received some attention in the literature. Mishel (1991) and Rolland (1994) have each addressed sustained uncertainty in chronic illness. Mishel (1990) reformulated her conceptualisation of uncertainty to address the issue of sustained uncertainty in

chronic illness suggesting that learning and growth rather than certainty are the outcomes of sustained uncertainty. Whereas, Rolland (1994) hypothesised that sustained uncertainty in chronic illness results in family strain. Based on the analysis of my data, I am advancing knowledge by offering a slightly different view of uncertainty by drawing out the intermediary function of interactions and reciprocity.

Mishel (1990) used critical social theory to analyse her theory of uncertainty and queried the outcome of returning to pre-illness equilibrium as proposed in her original theory. She felt that the crux of the problem with her original conceptualisation of uncertainty was the assumption that an ill person desires certainty and that the goal of care is a return to pre-illness equilibrium especially in chronically ill individuals. She suggested that in chronic illness physiological and emotional changes make returning to a pre-illness state an unrealistic expectation. Her theory revisions are based in part on findings from a qualitative study (King & Mishel, 1986) that reported some chronically ill individuals evaluated sustained uncertainty in a positive manner. The explanation of these findings was that individuals learn and grow through the experience of uncertainty.

Findings from this study differ slightly from Mishel's hypothesis that only a positive evaluation of uncertainty leads to learning and growth. In this study, uncertainty about the future ultimately led families to feel responsible for making changes. Some of these changes were viewed positively while others were viewed negatively. Most patients expressed the desire to resume former activities as much as the physical constraints of their illness would allow. Some patients viewed physical deterioration and the inability to perform simple tasks of daily living as a great loss while at the same time saw gain in other changes. For example, Mrs. Levesque could

no longer make a bed or do any simple household chores, had to sell her home, and move to her daughter's home. She was distressed about no longer being able to do her own housework. However, she and her daughter viewed moving into her daughter's home as an opportunity for them to resume their former close relationship. Hence, uncertainty seemed to lead to family interactions that resulted in family changes that were viewed as both positive and negative. Perhaps both positive and negative experiences could lead to learning and growth.

As for Mishel's hypothesis concerning certainty as an unrealistic expectation, neither patients nor families in this study verbalised certainty as the resolution of uncertainty. In addition, my findings raised questions concerning her hypothesis that return to a pre-illness state is an unrealistic expectation in chronic illness. Whether or not it was realistic or unrealistic to want to return to a pre-illness state was not the issue for patients or families. All patients except three (Mr. Martin, Mr. St. Louis, and Mr. McKenzie, who were in Rolland's terminal stage of illness) wanted to resume as much of their former daily activities as possible. Family members sought ways to adapt the home environment to preserve patients' abilities to carry out desired activities. Patient desire to resume former activities was evident but the ability to do so was constrained by the illness. Family members dealt with uncertainty by changing the environment—making it safer by moving the patient (Mrs. Levesque, Mrs. Brunette, Mrs. Pageau) or by having the patient monitored (Mrs. Brunette, Mrs. Roy) or by reducing the patient's work (Mrs. Brunette, Mr. Peterson). Reciprocity and family interactions triggered by uncertainty affected how patients and their families handled chronic illness.

Rolland (1994) raised the issue of uncertainty in chronic illness within the

context of temporality and family strain.

In chronic conditions, however, uncertainties and ambiguities often extend into the distant future, frequently with the expectation that the patient's illness will worsen and eventually result in death. Over time, a serious psychosocial strain on the family unit is unavoidable (p. 2).

Rolland's notion of temporality is similar to Mishel's term, sustained uncertainty. The data from my study support Rolland's contention that uncertainty in chronic illness persists over time. Analysis of the information gathered from informants suggested that uncertainty might occur throughout the course of chronic heart failure since uncertainty was evident during different phases of chronic illness. Uncertainty occurred during hospitalisation for an acute episode, during rehabilitation, and in the pre-terminal phase of illness. My findings enlarged on Rolland's hypothesis that family strain is unavoidable, since a wide range of responses including both conflict and increased closeness were found amongst family members.

Based on the analysis of my data I am offering a slightly different view of uncertainty than that of either Rolland or Mishel. Viewing the outcome of uncertainty as being either family strain or learning and growth does not fully capture the consequences that emerged from my data. My view of uncertainty draws out the intermediary function of interactions and reciprocity and ultimately takes into account both positive and negative consequences of the uncertainties experienced by these patients and their families. My data analysis suggested that uncertainty triggered family interactions. The interactions that happened between the patient and the family, combined with reciprocity between the illness and the family, produced outcomes that are unique to individual families. Interactions among family members elicited an

overwhelming sense of responsibility to take care of the patient and to protect the patient from harm.

FAMILY RESPONSIBILITY

Family responsibility emerged from the data through analysis of interactions that occurred between patients and family members. The uncertainties experienced by patients and families coupled with further deterioration of health acted as a catalyst to interactions between family members. Uncertainty, in concert with other factors such as the further deterioration of the patient's health resulted in family members feeling responsible for taking care of the patient. Family members often made drastic changes in their lives because of their overwhelming sense of being responsible for taking care of and protecting the patient.

Chronic heart failure not only affected the ill individual but also had enormous ramifications for the family. The impact of this uncertain, life-threatening, chronic illness on the individual reverberated throughout the family resulting in changes in living arrangements, relationships, and activities of daily living for both patients and families. The enormous changes that families made in their lives in response to the illness of a member illustrated the reciprocal influences of the illness on the family and of the family on the illness. The family was more than context for patient care. The family was a system of connected parts affected by and affecting the illness.

Properties, conditions, and consequences of family responsibility for taking care of the patient emerged from the data. I will argue that family responsibility had particular properties, that conditions in the various players and in the environment (system) contributed to family responsibility, and had consequences for the patient

and family.

Properties of family responsibility included characteristics of the patient and family. Characteristics of the patient that contributed to family members feeling responsible were wide and varied and included depression, strength, sadness, determination, fatalism, resistance to making changes, fear of loss of independence, fear of ruining existing relationships, and wanting to maintain previous patterns of living. Characteristics of the family were the need to take care of and protect the patient, cohesiveness of the family, and developmental needs of the family.

Conditions that precipitated family responsibility included deterioration in patient health status, recent death of a spouse, and practical environmental factors. Examples of environmental factors included the availability of someone or some place to monitor the patient, house size, and the distance family members lived from the patient. For family members (predominantly daughters) feeling responsible was precipitated by:

- being uncertain about what might happen if the patient was left alone,
- a history of taking care of the patient,
- the desire to look after the patient either by themselves or to have others do so in a safe environment (nursing home) where patients could be watched or monitored

The consequences of family responsibility encompassed social, emotional, and physical changes in family life. Social changes for family included alterations in relationships within and outside of the family. Emotional changes included increased family closeness and/or family conflict while physical changes involved making adjustments in living arrangements, household activities, and chores. Patients

predominantly sought to maintain living arrangements that existed prior to the illness crisis or sought emotional support by moving to be closer to family. Changes in living arrangements were primarily associated with protective behaviors exhibited by family members. Family members sought to protect the patient from harm either by moving into the patient's home (Mrs. Brunette), moving the patient to the family residence (Mrs. Levesque, Mrs. Pageau), or moving the patient (Mr. MacKenzie) to what was thought to be a safe environment (nursing home, residential home). Families also moved in order to strengthen existing close relationships or to resume habitual patterns of behavior. Family members made adjustments because they recognised that patients were no longer physically able to perform tasks of daily living, such as household chores. This inability was due to health deterioration that manifested as increased shortness of breath and fatigue. Recognition of their inability to carry out daily household tasks, acquiescence to family wishes, and their need for emotional comfort and physical support were conditions that precipitated changes for patients.

Patients experienced losses (loss of a home, of pets, of friends, of independence) and gains (not being alone, warding off depression, being with family) in association with moving. Family members also experienced losses and gains. Family members described the loss of mobility, of privacy, and of social activities. Gains included feeling more in control and being closer to a loved one. Conflict occurred between family members (Mrs. Brunette, Mrs. Houle) and between family members and the patient (Mrs. Pageau, Mrs. Roy, Mr. MacKenzie, and Mr. Peterson). Family members worried about taking too much away from the patient while at the same time expressing the need to watch or monitor the patient and keep him/her from doing activities prohibited by the doctor (Mr. Peterson, Mrs. Brunette).

Other family members made changes in their own lives such as taking early retirement (Mrs. Valenti) and arranging the environment to help the patient meet the need for personal autonomy (Mrs. Valenti, Mr. Peterson). As noted earlier, many patients wanted to get back to the way things were—to maintain their independence (Mrs. Pageau, Mrs. Roy). Families recognised this need and struggled with how to balance their need to protect the patient with the patient's need to be independent. The diminished ability of patients to carry out tasks of daily living and to be independent on others led to the expression of a range of patient feelings such as, guilt, frustration, acceptance, and depression.

Extending Knowledge of Family Responsibility

After uncovering the concept of family responsibility and delineating its properties, conditions, and consequences, I examined the literature to determine what had been written on this topic. I discovered that responsibility had been addressed somewhat in the cardiac literature. However, protectiveness had received much more attention.

Protective behavior by family members has been described primarily in terms of over protectiveness or over responsibility and has generally been portrayed in a negative light in the cardiac literature. I am proposing a more comprehensive, grounded explanation of patient and family responses to chronic cardiac illness with respect to family responsibility than what currently exists in the literature.

Numerous researchers have described spouses of acute myocardial infarction patients as over protective and vigilant. In particular spouses have been described as constantly watching and monitoring the patient for illness symptoms (Mayou, Foster

& Williamson, 1978; Gilliss, 1984; Johnson & Morse, 1990; McCrae, 1991). Over protectiveness has been described as being characterised by nagging, controlling, and nonsupportive behaviors (Hilbert, 1985; Wishnie, Hackett, & Cassem, 1971). Riegel and Dracup (1992) challenged the prevailing negative beliefs of many researchers concerning over protectiveness by family members. These researchers found that patients who described themselves as being over protected (getting more support from family and friends than wanted) reported less emotional distress, higher self-esteem, and less emotional reliance on others when compared to patients who saw themselves as receiving insufficient support. Protective and vigilant behaviours were both evident in my individual and family interview data. However, over protectiveness by either definition (spousal nagging, controlling behaviour, or providing excessive support from family and friends) was not evident in my data. Indeed, some families (Mrs. Brunette, Mr. Peterson) expressed concerns about the potential for being too protective and sought to balance the dependence/independence needs of patients. Vigilance such as wanting to watch or monitor the patient was evident during both acute hospitalisation and on an ongoing basis.

I contend that wanting to take care of and protect the patient were functional attributes of family responsibility. Family responsibility had multiple, complex consequences including such protective behaviors as moving the patient to a safe, monitored environment, taking over household chores, and/or avoiding situations thought to be emotionally stressful for the patient.

Family discord and cardiac invalidism have been attributed to family members being overly protective. Indeed, in a study of family adaptation to coronary artery disease, Patterson (1989) described family conflict as being the result of spousal over

responsibility for the patient's lifestyle changes. Analysis of the data also uncovered family conflict. However, family conflict was only one consequence of family responsibility. Family responsibility had multiple consequences for patients and family members that were complex. Family conflict and increased family closeness or solidarity occurred simultaneously in some situations. In addition, family members recognised that protective behavior could create a personal autonomy dilemma for the patient and impinge on the social, emotional, and physical world of both the patient and family. The interactive or reciprocal impact of the family on the illness and the illness on the family was evident.

Based on the findings from this study I am proposing a broader, more balanced picture of family responses to chronic heart failure than previously described in the cardiac literature. Potentially positive and negative consequences of family responsibility for taking care of and protecting the patient came from the data. In an article that described a concept named "family protectiveness", Tapp (1993) also proposed a more balanced explanation of family responses to cardiac illness. She developed her concept of family protectiveness from a review of the literature on protectiveness in families experiencing ischemic heart disease. In contrast to my contention that family responsibility is a central concept of family responses to chronic cardiac illness, Tapp depicted responsibility as a dimension of family protectiveness. Family responsibility emerged from my data as a central concept with taking care of the patient and protecting the patient from harm being properties of responsibility.

Tapp further proposed that family protectiveness is a continuum with family adjustment at one end and family conflict at the other. The findings of my study challenge her conceptualisation of a continuum. As described earlier in this chapter,

family conflict and closeness were seen simultaneously which suggests that a continuum may not be a helpful way of viewing family responses to chronic cardiac illness. Furthermore, as previously noted, families in this study were acutely aware of the need to balance their desire to take care of and protect the patient with the patient's need for independence or personal autonomy.

In the context of family responsibility, the connections between the responses of family members to the illness and to each other were strongly evident. Indeed analysis of study data illustrated the reciprocal effects of the illness on the family and of the family on the illness. This new knowledge furthers understanding of the potential consequences of family responsibility and may help the nurse in assessing patient and family needs in a chronic heart failure situation.

In the following section I will argue that supportive nursing care as defined by nurses, patients, and family members involved an integration of physical, information, and emotional needs. When nurses met these needs, patients then experienced a sense of control and families felt comforted and secure. Supportive nursing care as described by nurses, patients, and families took into account both the patient and the family and addressed the nurse's struggle of adequately caring for both.

SUPPORTIVE NURSING CARE FOR PATIENTS AND FAMILIES

Properties, conditions, and consequences of supportive nursing care for patients and families emerged from the data. Giving information and giving emotional support were categories that came from the patient, family, and nurse interview data concerning supportive nursing care. Giving physical/technical care was a

subcategory of giving emotional support.

Giving information involved properties of explaining and knowing. Giving information included such activities as explaining the purpose and meaning of medications, symptoms, and equipment as they pertained to the unique patient and family situation while the patient was hospitalised. Whether during hospitalisation or after discharge, the information that was viewed as useful by individuals and their family members addressed the uncertainties peculiar to their specific situation. Giving information also included providing guidance about and connections to relevant, available community resources. Conditions that precipitated the giving of information were that patients and/or families directly asked for information, that nurses assessed that there was a need for information, that nurses had the time and resources to give information, and that nurses valued such an activity. Knowing or acquiring relevant knowledge led to a sense of personal control for patients and was described as useful by family members. When patients and families did not ask for information, nurses often assumed there was no need. When individuals and family members felt they had not received adequate information (Mrs. Levesque, Mr. Peterson) or did not understand the information given (Mrs. Levesque), then uncertainty, confusion (Mrs. Levesque, Mr. Peterson), and family conflict (Mrs. Brunette) occurred.

Giving emotional support involved the nurse understanding and having empathy for the patient. Other characteristics or properties of emotional supportive nursing care for the patient included the ability of the nurse to be compassionate, to be interested in the patient's pain or worries, and to listen. Properties of emotional support for family members included being allowed to be with the patient, being helped to interact with the patient in ways meaningful for the family member, being

able to call the nurse at any time, having nurses listen and having nurses attend to requests. For patients and family members the giving of physical/technical care by the nurse was connected to giving emotional support and was then linked to viewing the nurse as competent. This sense of confidence in the nurse's competence was evident in the intensive care unit (Mr. MacKenzie, Mrs. Moore) and in the cardiac rehabilitation setting (Mrs. Levesque, Mrs. Moore). Believing that the nurse was competent led patients and family members to feel confident and reassured. Conditions that dictated whether or not nurses gave emotional support to patients and their families were:

- the amount and extent of support requested by patients and families
- the nurse's skill and knowledge in providing emotional support
- the nurse's belief that providing emotional support is part of nursing work
- the acuity of the illness.

The acuity of the patient's health status and the highly technical, complex nature of care were frequently described by all study participants as reasons for nurses being unable to provide informational or emotional supportive care. Patients, family members, and nurses said that health care cutbacks combined with a shift in the delivery of health care from the hospital to the community had resulted in an increase in the severity and acuity of nurses' workloads. Changes in the severity and acuity of workloads translated into less time for providing informational and emotional supportive care, particularly for floor nurses. However, closer examination of the data also revealed that there were few if any hospital system mechanisms such as documentation to reinforce supportive nursing care. Despite these difficulties emotionally supportive nursing care created a state of relaxation for patients and was

described as comforting and morale boosting by both patients and families. Emotional support reinforced both personal and family strength or hardiness.

Differences in the effectiveness of the coordination role of nurses working on the floor and in the intensive care unit as compared to the rehabilitation setting were evident. For some patients and family members the coordinating work of the nurse in the hospital setting (contacting doctors, getting medication orders, arranging referrals to Victorian Order of Nursing, etc.) was not obvious, did not lead to desired results, and consequently was viewed by patients and their family members as ineffective. Nurses were perceived as not making or not being able to make connections to the resources (doctors, information, rehabilitation referrals, and palliative care referrals) that the patients and/ or their families felt they needed. In contrast, the patient data suggested that the coordination work of nurses in a rehabilitation setting was observable, valuable, and effective. As just one example, Mrs. Moore described how the nurse assessed her symptoms and immediately made a referral to the nutritionist that ultimately resulted in resolution of troublesome difficulties she was having with eating. Mrs. Moore's nurse in the rehabilitation setting saw part of her role as coordinating a multi-disciplinary team—making connections between patients, their families, and the resources that patients and families identified as being needed through interaction with the nurse.

Integration of Physical, Informational, and Emotional Support

Giving physical, informational, and emotional support were intertwined in the words of many patients, family members, and nurses. Patients and families viewed the provision of these kinds of supportive nursing care as interactive. Nurses described the connection between physical and emotional care in terms of the creation

of a healing or therapeutic environment (Mrs. Moore's nurse in ICU and in the rehabilitation program). All of the nurses who were identified by patients as having provided supportive nursing care gave all of these kinds of care. However, for some nurses physical/technical care was the priority and giving information and emotional care was viewed as secondary and expendable. Whereas for other nurses physical technical care was inextricably linked with giving emotional support and giving information about the patient's care to both the patient and the family.

Extending Knowledge of Supportive Nursing Care

The similarity between the supportive nursing activities performed by nurses as described by patients, their families, and nurses that emerged from my data and those uncovered by other researchers investigating different illnesses and populations was striking. Indeed the support aspects of nursing care described by Whyte (1994) in a study of children with cystic fibrosis and their families are very similar. Aspects of nursing support that Whyte outlined included giving information, explaining the meaning of investigations, answering questions, listening, providing a link between the clinic and the home and between the home and the school, and providing help with child care. In this study, supportive nursing care involved the giving of information (explaining symptoms/equipment/medications) and making connections with resources, giving emotional support (listening, being there), and giving physical/technical care. The similarities in supportive care for patients and families in the context of vastly different illnesses and patient populations may suggest that aspects of supportive nursing care cut across illnesses and age groups.

Craft and Willadsen (1992) used the data gathered from 54 of 130 nurse

experts in the United States to identify and categorise family nursing interventions. These researchers labelled, defined, and identified critical and supporting activities for nine family interventions, one of which was family support. However, their detailed description of the nursing intervention family support represented the nurse expert perspective alone and so was not grounded in the perspective of relationships between the elements of family systems nursing which are patient, family, nurse, and illness. The activities subsumed beneath the family support intervention were categorised into 14 critical (major) and 14 supportive (minor) activities. Critical activities included those directed toward the emotional status and coping of the family. Whereas supporting activities were specific to individual situations. Many of the critical activities listed such as listening, answering questions, facilitating communication between patient and family or between family members are similar to those identified in this study. However, whether the focus of family care is on the individual in the context of the family (family as environment) or on the family in the context of the individual (family as patient) or both was not delineated.

In contrast to Craft and Willadsen (1992), the findings of this study extend knowledge of family nursing theory by conceptualising supportive nursing care for patients and their families as an integration of physical, emotional, and informational support. Supportive nursing care created a therapeutic environment in which patients and their families feel comforted and reassured. As discussed earlier in the family nursing theory section of this chapter, supportive nursing care focused on the individual in the context of the family (family as environment), the family in the context of the individual (family as patient), or both. The focus of supportive nursing care fluctuated between the individual and the family. This fluctuation

depended upon the setting, the skill and knowledge of the nurse, the acuity of the patient's illness, and the amount and type of family demands for supportive nursing care.

Corbin and Strauss (1992) have also written about supportive nursing care in the context of their chronic illness trajectory. Comparative analysis of their work and the findings of this study offer an important opportunity to integrate the knowledge gained in this study about family nursing into an existing nursing model.

Family Nursing and the Corbin and Strauss Model

Corbin and Strauss (1992) developed a chronic illness trajectory framework that is an extension of the earlier work by Strauss et al. (1984) which influenced the interview framework used in this study. Their trajectory framework is described as being "a substantive theory about chronic illness, developed specifically to provide insight and knowledge about chronic conditions in general" (p. 10). Since the interviewing framework used in this study was influenced by the Strauss et al. (1984) framework and by the Wright and Leahey (1984, 1987, 1994) family assessment work, it is interesting to note that there are similarities between my findings and those of Corbin and Strauss (1992) as well as other researchers in the field of chronic illness (Thorne, 1993). However there are some differences as well.

The Corbin and Strauss (1992) expanded trajectory framework focuses on the notion those chronic illness variations and adjustments occur over time and it encompasses eight major concepts. These concepts are trajectory, trajectory phasing, trajectory projection, trajectory scheme, conditions influencing management, trajectory management, biographical and every day living impact, and reciprocal

impact.

Trajectory

Trajectory refers to the course of the chronic illness or condition and is 'shaped by' the ill person, family, and health care professionals. It deals with individuals' perceptions of situations, their responses to those perceptions, and the organization of work that is involved. Hence, in the Corbin and Strauss model the family is not conceptualised as a unit of care: rather, each individual is seen as unique and perceiving and reacting to illness on an individual basis. In this study, individual participants had unique reactions but it was also the case that families had family unit responses to illness (the Moore family, Chapter 8; the Pageau family, Chapter 6; and the Brunette family, Chapter 7).

In the Corbin and Strauss framework there are various kinds of trajectories—illness, biographical, dying—all have the qualities of duration, movement, predictability, and shape. Illness trajectory refers to the course of the disease. Biographical trajectory although not described in depth, refers to the past history or "life course" of the ill person apart from the illness (Corbin & Strauss, 1992, p.18). The dying trajectory refers to the work of dying which is the ultimate outcome of the chronic illness trajectory. Work that is necessary to shape or manage the illness trajectory (the tasks of chronic illness) is performed by staff and by clients and their families. The inclusion of a family nursing perspective led to uncovering family information that might not otherwise have been revealed and thus emphasises the importance of incorporating a family nursing perspective and family assessment into the care of chronically ill patients and their families. The incorporation of a family perspective allowed the nurse to address issues beyond the level of family as context

for patient care. Mrs. Moore's ICU nurse did not just provide the family with information to help them assist with Mrs. Moore's care: she also provided care to family members to aid them in the emotional distress each experienced in response to the acute, life threatening status of Mrs. Moore's health. She intervened to help each of them as members of a family unit experiencing emotional distress evoked by the illness of the family member.

Trajectory Phasing

Trajectory phasing is comprised of subphases through which a chronic illness condition may progress allowing for the multiple variations that can occur within each phase. In my work, Rolland's typology of the stages of chronic illness was used in my description of the trajectory of chronic heart failure (see Family Profiles, Chapter 5). The Corbin and Strauss framework is task oriented whereas Rolland's phases (crisis, chronic, and terminal) provide a developmental understanding of the history of a disease. Both elements are important.

Trajectory Projection

Trajectory projection represents the anticipated view of the illness, which is influenced by the meaning of illness, symptoms, past life experiences, and time. Essentially trajectory projection represents notions of what is going to happen in the future. Uncertainty has been identified as a concern for patients and their families in chronic illnesses (Corbin & Strauss, 1988; Wiener and Dodd, 1993). Wiener and Dodd (1993) studied individual cancer patients and discovered what they called a 'temporal' aspect of uncertainty, which is similar to my 'uncertainty about the future'.

However, my study data uncovered uncertainty about the future not just from the perspective of the individual but also from the perspective of the family, as individual

family members and as a group. Uncertainty triggered interactions between family members, and between the ill person and the family that evoked a sense of family responsibility to look after and protect the patient. What is going to happen in the future emerged as a major concern for several families (Chapter 6—the MacKenzie family, Chapter 8 the Roy family, the Martin family). Corbin and Strauss suggest that each person including, patient, nurse, doctor, and family member hold their unique view of what the course of illness will be. In my study, individuals did hold unique views however, there was also congruence between patient, family, and nurse views of the course of illness when nurses were identified as being supportive. This is particularly evident in the Moore family.

Trajectory Scheme

The fourth phase, 'trajectory scheme' encompasses three tasks: 'shaping the overall illness course, controlling symptoms, and managing disability' (Corbin & Strauss, 1992, p. 17). The trajectory scheme includes both formal medical treatment as well as a multitude of other 'alternative' forms of care such as prayer, positive thinking, meditation, acupuncture etc. Study data from this study revealed that traditional medical treatment inevitably involved anywhere from 10 to 12 different medications, all of which were potentially life threatening if they were inadvertently misused. Other forms of medical technology were not evident except in the ICU on a short-term basis. Two of the non-conventional treatments were evident: prayer and positive thinking. In my study, the use of positive thinking or looking on the optimistic side and having hope were strategies advocated by many patients and families alike.

Conditions Influencing Management

Conditions influencing management refer to the multiple conditions that affect “how and to what degree someone’s trajectory scheme” is actualised (Corbin & Strauss, 1992, p. 17). Conditions described by Corbin and Strauss include technology and its side effects, resources (manpower, social support, knowledge and information, time and money), past experience, motivation, setting of care (home or health facility), life-style, nature of the interactions and relationships between persons involved in managing the illness trajectory, type of illness, degree of physiologic involvement, nature of the symptoms and the nature of the political and economic climate. In my study, many of the conditions identified by Corbin and Strauss were evident in most families.

Technology and setting of care are two areas that warrant discussion as they provide further support for the inclusion of a family nursing perspective. The complexity of technology combined with the complexity of family care hindered but did not prevent the nurse from attending to the divergent needs of family members and the patient in the critical care setting. In both ICU and cardiac rehabilitation settings the nurse’s technical skill and technology were portrayed by patients and family members in a positive light and seen as keeping the patient alive (the Pageau family) or safe (the Moore family). Corbin and Strauss (1992) tend to describe the negative aspects of technology although they do identify watching and monitoring as critical functions that ‘shape’ the course of illness just as patients, families and nurses did in this study. It may well be that technology is viewed differently in chronic heart failure because it is usually short term and intermittent as opposed to the technological dependency seen with for example chronic renal failure patients on

dialysis (Stapleton, 1986).

Trajectory Management

Trajectory management refers to the process used to 'shape' the illness course and involves controlling symptoms and side effects, handling crises, preventing complications etc. Controlling symptoms and side effects were critical aspects for most informants in this study. Learning to recognise what symptoms meant and knowing what to do about them was crucial for the Roy family, the Pageau family, the Levesque family, and for the Peterson family. The side effects of medications were critical elements of care for Mrs. Moore and Mrs. Valenti. Uncertainty about what symptoms meant, what to do after discharge from hospital and what the future would hold emerged as a central concern.

Biographical and Every Day Living

Biographical and every day living impact represent 'life course' and have to do with identity—adjustments are continually being made in response to the changes induced by the illness. Everyday life activities refer to the actions of daily living. The impact of the uncertainty of chronic heart failure on day to day living was powerfully evident in this study. The uncertainties of chronic heart failure triggered interactions between family members and between the ill person and family members resulting in the family feeling responsible for taking care of and protecting the patient. Consequences of these interactions include adjustments in living arrangements, activities of daily living, and relationships, which have previously been described in detail.

Reciprocal Impact

The last part of the trajectory is called reciprocal impact and receives the least

attention of all the aspects of the trajectory despite being described by Corbin and Strauss as a “very important concept in the trajectory framework” (p.19). Reciprocal impact refers to the interaction between illness, biography, and everyday activities. In my study, interaction and reciprocity centre on the illness and the family and vice versa as well as on interactions between family members and between the ill person and family members. Connections between uncertainty, interactions and a concept called family responsibility have been proposed. Interactions are portrayed as triggers to family responsibility which is characterised by the family wanting to take care of and protect the patient and has multiple consequences in terms of family living arrangements, activities of daily living and relationships.

Corbin and Strauss (1992) have developed a model for the delivery of nursing care that applies the trajectory framework to nursing practice. The model is based on the metaparadigm of person, environment, health, and nursing and according to the authors is “philosophically grounded in chronicity” (p.19). However, person appears to refer to the patient and family seems to be viewed as environment (context). The authors further define the goal of nursing as being to shape the illness course while maintaining quality of life. Again, the focus is the ill person and family is context or background, primarily there to assist the patient in shaping the course of illness. They suggest that the nurse does this by providing ‘supportive assistance’. Supportive assistance involves each aspect of the chronic illness framework, ie. prevention of illness, and management of chronic illness, in conjunction with “biographical needs, and performance of everyday living activities” (Corbin & Strauss, 1992, p. 21).

Nursing process is proposed as the mechanism for actualising supportive assistance. Specific tasks are outlined including direct care, teaching, counselling,

making referrals, making arrangements, and monitoring. Many of these tasks outlined are strikingly similar to the findings concerning supportive nursing care in this study. However, differences lie in the decisions about when and how or even whether the focus of care shifts from ill person to the person in the context of family, to the family as a unit of care. Furthermore, assessing family function, development and structure revealed family concerns that might well not have been uncovered by the Corbin and Strauss model. For example, functional assessment yielded important information from several families, such as the Moore family - son's schizophrenia or the Pageau family - son's brain injury. Assessment of family development uncovered conflict between the patient's illness care and developmental needs of the family (the Roy family). These all represent family concerns that might well not have been uncovered by the Corbin and Strauss model.

Corbin and Strauss (1992) most definitely include family but family seems to be depicted as context for patient care. Reciprocity between the illness, biography and activities of daily living are in the context of the course of the patient's illness. The question raised by this study is would their nursing model benefit from expansion of the metaparadigm to include family and family assessment? Data from my study support the argument for an incorporation of a family nursing perspective into the Corbin and Strauss model. Family nursing does not stand alone: it is not a model, rather it is, I argue, an essential element of the nursing metaparadigm when the metaparadigm is reconfigured to include a dynamic conception of person as a part of the family system.

This study has examined family nursing and supportive nursing care for patients and family in the context of Chronic heart failure which can be linked to the

broader chronic illness literature.

Chronic Illness

Contributions to the understanding of the chronic illness experience have been made by a wide variety of disciplines and perspectives. Chronic illness is a growing phenomenon in western society (Thorne, 1993). The demands of chronic illness have been studied psychologically in terms of the ongoing need for coping and adaptation (Moos & Tsu, 1977; Cohen & Lazarus, 1983; Corbin & Strauss, 1988; Pearlin & Skaff, 1996). A social interactive perspective has been used to study the chronic illness experience and has revealed alterations in human relationships (Strauss, et al., 1984; Corbin & Strauss, 1988; Wiener & Dodd, 1993). Studies from various disciplines have provided some insight into patterns of disease and factors influencing symptom distress and help seeking behaviour (Alonzo, 1984; Mechanic, 1986; 1989; Druley & Townsend, 1998).

In arguing for closer and more examination of the subjective experiences of chronic illness, Thorne (1993) suggests that “one needs to explore shared elements in the experience of many people in order to begin identifying patterns that might explain common subjective features” of the chronic illness experience (p. 6). Perhaps among the most important elements in the subjective experience of chronic illness is the notion that people experience chronic illness within their families. Although nursing care of the family occurred because of the ill patient, the complexity and disruptions of chronic illness required that the focus of supportive nursing care shift between the patient and the family unit. My study findings confirm the value of a family nursing theoretical perspective (Robinson, 1995) that allows the

focus of care to shift from patient, to family unit as well as to center on both simultaneously. There are difficulties inherent in providing simultaneous care, the critical nature of the patient's condition being one evidenced in this study. However, such difficulties should not preclude critical examination of the health care system to allow nurses to provide needed family care.

CONCLUSIONS

The analysis of the accounts of study participants presented in this thesis advances understanding of supportive nursing care for patients and families in the context of an acute episode of chronic heart failure and ongoing living with this chronic illness. In-depth interviews gave access to the personal accounts of patients, family members, families, and nurses during acute episodes, during pre-terminal situations, and during rehabilitation. Constant comparative analysis of the interview data revealed two important concepts—uncertainty and family responsibility. A third concept, supportive nursing care, was derived from the responses of patients, their families, and nurses to a question about what supportive nursing care meant to them.

Living with chronic heart failure, a condition distinguished by acute, potentially life-threatening episodes was an experience characterised by uncertainty for patients and families alike. The view of uncertainty proposed here, grounded in the data, draws out the intermediary function of family interactions and reciprocity and takes into account a range of consequences experienced by these patients and their families. I contend that uncertainty triggered family interactions.

The uncertainty experienced by patients and families combined with further

deterioration of health catalysed interactions between family members that initiated an overwhelming sense of family responsibility to take care of and protect the patient from harm. Consequences of family responsibility involved major adjustments in living arrangements, relationships, and activities of daily living and reflected the reciprocal relationship between the ill family member and the family. The decisions made by families demonstrated the utility of systems theory as a foundation for family nursing.

How does this study contribute to theory for nursing? According to Glaser (1978) a substantive theory is developed from a substantive or empirical area such as 'patient care' or 'professional education'; on the other hand 'formal theory is theory developed for a formal or conceptual area such as 'status passage' or 'stigma' (p. 144). The two concepts of 'uncertainty' and 'family responsibility' that emerged from this study are more akin to the latter. Both formal and substantive theories are mid-range theories falling between 'minor working hypotheses and grand theories'. Corbin and Strauss (1992) described their 'trajectory framework' as a substantive theory (p.10) because it deals with the substantive or empirical area of chronic illness where theory has constantly been broadened by comparative analysis between or among substantive chronic illness groups. By contrast the theory generated by this study represents the beginning of a formal theory. Uncertainty and family responsibility are concepts that could arguably transcend chronic congestive heart failure and other chronic illnesses to other life circumstances. Perhaps the hypothesis that uncertainty triggered interactions that led to family responsibility to take care of and protect individual family members would hold true in different life circumstances, such as couple infertility, or families experiencing a missing person. However, in the

words of Glaser (1978) "A one area formal theory still remains in actuality treated as a substantive theory which could possibly later be generalised by comparative analysis" (p.145). In this discussion chapter I have compared the theory generated from my data concerning uncertainty and family responsibility with other theoretical conceptualisations (eg. Mishel, 1990; Rolland, 1994; Tapp, 1993) and with other comparative illness groups. In order to broaden the scope and density of my proposed theory on a formal level many more investigations of different substantive areas would be needed.

Supportive nursing care for some patients, their families, and nurses evolved as an integration of physical, emotional, and informational support to create an environment in which patients and their families felt comforted and reassured. In life-threatening situations, the physical care of the patient was the priority for families and nurses. However, some nurses did not exclude the family when patients were critically ill. The focus of supportive nursing care fluctuated between the patient, the family, or both. The focus seemed to depend upon the setting, the skill and knowledge of the nurse, the acuity of the patient's illness, and the amount and type of family demands for supportive nursing care.

This study contributes to theoretical clarification of family nursing by shedding light on the dilemma of providing patient and family care simultaneously and explaining some of the factors that influenced family care. Specifically, this research data supports a dynamic view of family nursing that allowed the nurse to focus in some situations on the family as context for patient care or in other situations on the family as the unit of care. Such a dynamic view challenges the conceptualisation of family nursing as a continuum (Robb, 1998). Family nursing, I argue, is an essential

element within the nursing metaparadigm if person is seen as part of a family system. I have further clarified that the delivery of family nursing may be a function of the context of nursing care (ICU or rehabilitation setting) and the knowledge and skill of the nurse. Fluctuation between caring for the family as context for patient care and family as unit of care was explained by the acuity of the patient's illness and the kind and amount of support required by family members. Finally, I am proposing the incorporation of a family nursing perspective into the Corbin and Strauss (1992) model that allows for the metaparadigm concept of 'person' to be conceptualised as individual as part of a family system and have proposed the integration of a family assessment component as well.

Implications for Practice, Education and Future Research

The new knowledge presented here has implications for nursing practice, education and future research. Implications for practice, education and research derive from the knowledge gained about uncertainty, family responsibility, and supportive nursing care.

Practice

Exploring and describing uncertainty and family responsibility in terms of the interaction patterns of the family system assisted the nurse to appreciate the reciprocal influences of the ill person on the family and of the family on the ill person. Viewing patient and family responses to the uncertainties of chronic heart failure within an interactive, family systems perspective may provide insight into how nurses can give supportive nursing care. An understanding of the potential consequences of the

uncertainties experienced and the resultant family responsibility for taking care of the patient could help the nurse to make sense of observed responses of the family.

Interventions could then be developed together with the family to address specific difficulties or problems identified by the patient and family. Interventions could be directed at the system level (individual, dyadic, family, social system or community system) with the most likelihood of creating the changes desired by the family. In addition, family responsibility for care of the patient could be seen as either a family strength that facilitates adjustment to illness or as an inappropriate response to illness. Both health care systems and individual practicing nurses need to be encouraged to use the knowledge gained in this study concerning uncertainty, family responsibility, and supportive nursing care in chronic heart failure and integration of that knowledge into models like the Corbin and Strauss model needs to be developed.

Education

Supportive nursing care as defined by patients, families, and their nurses involved an integration of information giving, emotional support, and physical care. The setting (ICU or rehabilitation), the competing demands of complex patient and family care, and the competence of the nurse influenced the level of family nursing offered. Keeping this understanding in mind, educational strategies that facilitate the nurse's ability to provide supportive nursing care for patients and their families need to be developed. Implications for nursing education include the need to determine whether family nursing is part of current nursing curricula throughout the United Kingdom, an undertaking that has occurred in Canada (Bell & Wright, 1990). As well, nursing curricula content could be assessed to determine whether and how much content there is on chronic illness, family responsibility, and uncertainty. Knowledge

gained from this study about uncertainty, family responsibility and supportive nursing care could be incorporated into nursing course content, continuing education workshops, networking, and conferences.

Research

Strategies to initiate health care system changes to incorporate family nursing into practice could include the implementation of an action research study. Nurses, patients, and family members identified simple system changes that would support the inclusion of family in patient care. The results of this study could be presented to nurses and perhaps a family assessment sheet, possibly based on the work of Wright and Leahey (1994), could be developed with them. The delivery of supportive nursing care to patients and their families goes beyond being the sole responsibility of the individual nurse to being the responsibility of the larger hospital or community system. System changes would be essential to nourish and sustain the simultaneous delivery of supportive nursing care to patients and their families. Institutional mechanisms such as assessment and documentation guidelines are one way to help nurses be accountable for providing supportive nursing care to patients and their families.

The underlying principles of grounded theory indicate that in order for generalisation to occur theory must be tested to verify utility for practice. Hence, the insights and contributions to the advancement of knowledge that have been offered here should be tested with different patient and family populations. Although supportive nursing care and the uncertainties experienced by patients and their families may not be greatly changed, family responses may differ with different patient illnesses, families, and cultures. Specifically, family research is needed to test the hypothesis that uncertainty combined with further deterioration in health trigger

interactions between family members and initiate an overwhelming sense of family responsibility to take care of and protect the patient from harm.

CHAPTER 10

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APPENDIX A: TABLES

TABLE 1
DESCRIPTION OF FAMILY UNITS

Family	Age	Point of Contact	Marital Status	Living Arrangement Prior to Illness	Patient Illness History And Admissions	Family Illness	Interviews Conducted
Mrs. Roy	77	Hospital	Widow (20 years)	Daughter	Diagnosed 16 years ago; 3 in the last 4 months	Grand-daughter Crohn's Disease	Patient, daughter, grand-daughter, nurse, family
Mrs. Pageau	61	Hospital	Widow (6 months)	Alone	Diagnosed 5 years ago; Once in the last year	Son old head injury	Patient, 2 sons, nurse.
Mrs. Brunette	75	Hospital	Widow (2 weeks)	Husband now Daughter	Diagnosed 20 years ago; 2 in the last 2 weeks	Daughter ? heart disease; grandson Down's Syndrome;	Patient, daughter, daughter in law, nurse, family (8)
Mr. Martin	66	Hospital	Married	Wife	Cardiac arrest 7 years ago 4 or more in last year	Wife Arthritis; son recent cardiac ablation	Patient, wife, son, nurse, family.
Mr. Peterson	50	Hospital	Married	Wife, Son	Diagnosed 1 month ago; 2 in the last 2 weeks	Brother, heart transplant 6 years ago is now dying	Patient, wife, son, nurse, family
Mrs. Valenti	64	Rehabilitation	Married	Husband	Diagnosed 18 years ago; 3 in the last 15 years	Daughter profoundly deaf; husband hypertension	Patient, husband, daughter, nurse, family
Mr. St. Louis	69	ICU	Married	Wife	Mitral Valve surgery 6 years ago; 3 in the last year	Wife also caring for her elderly mother with a fractured hip	Patient, wife, son, nurse (patient died)
Mr. MacKenzie	67	ICU	Widower (4 years)	Residential Home	Diagnosed 3 years ago; 2-3 times in the last year		Patient, son, nurse
Mrs. Moore	55	Rehabilitation	Married	Husband	Heart Valve Disease 30 years; surgery 12 years ago; twice 2 years ago; once in the last year	Son has Schizophrenia	Patient, husband, daughter, 2 nurses (ICU and rehab), family
Mrs. Levesque	59	Rehabilitation	Widow (14 years)	Alone	Diagnosed 7 years ago; once in the last year		Patient, daughter, nurse, family
Mrs. Houle	50	Rehabilitation	Married	Husband	Diagnosed 6 months ago; once in the last year	Husband has Chronic Stress Syndrome	Patient, husband, daughter-in-law, family

TABLE 2
NURSE PROFILES

Nurse for Family Unit #	Age	Gender	Employment history	Past experience	Place of employment	Education
Family # 1	46	Female	25 years	Coronary Care Unit, ICU	ICU	College
Family # 2	33	Female	8 years	Medical floor	Medical floor	College; enrolled in Post RN program
Family # 3	21	Female	1 year	Medical floor	Medical floor	College; enrolled in Post RN program
Family # 4	54	Female	34 years	Surgical floor, Medical floor	Medical floor	Hospital program; ECG and refresher courses
Family # 5	27	Female	5 years	Medical floor	Medical floor	University BScN
Family # 6	42	Female	20 years	Psychiatric and Medical floors 2 years; ICU 9 years, Cardiac Rehabilitation 8 years	Cardiac Rehabilitation	Hospital; exercise physiology certificate
Family # 7	41	Female	20 years	Neuro-surgical floor 2 years; Medical-surgical floor 2 years; ICU 16 years	ICU	College; ACLS certificate; Critical Care Course
Family # 8	28	Female	6 years	Medical floor 6 months; Surgical floor 1 year; ICU 5 years	ICU	College
Family # 9	31	Female	8 years	Surgical floor 2 years	Cardiac Rehabilitation	College; exercise physiology certificate
Family # 9	33	Female	11 years	Surgical floor 1 year, ICU 10 years, 7 years as University lecturer and clinical teacher	ICU	University BScN, MHSc
Family # 10	31	Female	8 years	Surgical floor 2 years	Cardiac Rehabilitation	College; exercise physiology certificate
Family # 11	31	Female	8 years	Surgical floor 2 years	Cardiac Rehabilitation	College; exercise physiology certificate

Note: ICU = Intensive Care Unit; ACLS = Advanced Cardiac Life Support; BScN = Bachelor Science of Nursing, MHSc = Master of Health Sciences; Post RN = Registered Nurse

TABLE 3**Transcription Conventions**

Symbols	Meaning
1. Participants	
ER	The Interviewer
N	Nurse
D	Daughter
GD	Granddaughter
S	Son
DIL	Daughter-in-law
DIL2	Second daughter-in-law
2. Phrases	
.	Indicates a one second pause between utterances
3. Intonation	
CAPITAL LETTERS	Marks an increase in the voice tone relative to previous talk
4. Gestures/Clarifying Information <i>(Italics)</i>	Gestures used by the participants, tone of voice and explanatory information are included in italics in brackets.

TABLE 4
Interview Guide

Potential Questions Adapted from Strauss et al. 1984

DEALING WITH THE COURSE OF CHRONIC HEART FAILURE

- Can you tell me about your/the patient's illness from when it first started up until now?

PREVENTING AND MANAGING ILLNESS CRISES

- Can you tell me what brought you/the patient to the hospital? How did you/the patient decide to call the doctor or go to the hospital? What helped you/the patient to make the decision?

CONTROLLING SYMPTOMS

- Can you tell me about the symptoms that brought you/the patient to the hospital? (Cues: What are they? When did they happen? What do you think causes them?) How can you/your family help you/the patient to deal with these symptoms? What can the nurse do to help?

MANAGING TREATMENT REGIMENS

- Can you tell me about the treatment of your/the patient's illness (Probe: How do/does you/he/she manage medications, diet, physical activity?) What can the nurse do to help?

NORMALIZING LIFESTYLE AND INTERACTIONS WITH OTHERS

- Can you tell me how your/the patient's illness has affected your family living? (Probe: By that I mean, can you tell me about family social activities? such as leisure? work? chores? Have these changed since you/the patient have/has been in the hospital?) What can the nurse do to help?

RECOGNIZING FINANCIAL IMPLICATIONS OF CHRONIC ILLNESS

- Can you tell me how illness has affected family finances?
- How can the nurse help?

PSYCHOLOGICAL, MARITAL, FAMILY PROBLEMS

- What has the emotional impact of this illness been for you/the patient and your family?
- How can the nurse help?

Can you tell me what supportive nursing care means to you as a nurse/patient/family member?

APPENDIX B: ETHICAL DOCUMENTS

**Laurentian
University**

Ramsey Lake Road
Sudbury, Ontario
Canada P3E 2C6

(705) 675-1151, ext. 3204

**Université
Laurentienne**

Chemin du lac Ramsey
Sudbury (Ontario)
Canada P3E 2C6

(705) 675-1151, poste 3204



School of Graduate Studies
and Research
École des études supérieures
et de la recherche

This is to certify that the research proposal entitled Family, patient and nurse experiences of supportive care in chronic cardiovascular illness (Ph.D thesis), (1995-09-01)

Submitted by Ellen Rukholm

has passed an Ethics review by the Laurentian University committee for the evaluation of Research involving Human Subjects

Note: this approval covers only the documents submitted, in the language in which they have been submitted. Any changes to questionnaires or procedures must be re-submitted to the Committee, as stated on the form.



SUDBURY MEMORIAL HOSPITAL

865 REGENT STREET SOUTH, SUDBURY, ONTARIO P3E 3Y9
PHONE (705) 671-5604 FAX (705) 671-5656

ESKO VAINIO, M.H.A.
EXECUTIVE DIRECTOR

4 December 1995

Ellen Rukholm
School of Nursing
Laurentian University
Ramsey Lake Road
Sudbury, Ont. P3E 2C6

Dear Ms. Rukholm:

The Ethics Committee considered your request and the material submitted regarding the research proposal, "Family, patient, & nurse experiences of supportive care in chronic cardiovascular illness", at its meeting held 15 November 1995.

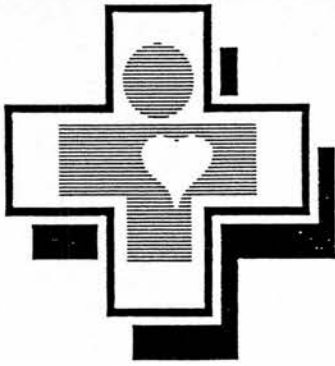
The Ethics Committee approved your research proposal; the Board of Governors has also approved this, at its meeting on November 30th. Therefore, you can proceed with your request.

I trust this is satisfactory.

Sincerely,

David Innes, Chair
Ethics Committee

☺ sn



SUDBURY GENERAL HOSPITAL
OF THE IMMACULATE HEART OF MARY

Sisters of St. Joseph
of Sault Ste. Marie
Incorporated 1937

May 23, 1996

Professor Ellen Rukholm
Laurentian University
School of Nursing
Ramsey Lake Road
Sudbury, Ontario
P3E 2C6

RE: Research: To Explore Family Members, Nurses and Patients
Perceptions of the supportive nursing care that nurses provide
to the family during acute episodes of chronic cardiovascular
illness as well as after hospital discharge.

Dear Professor Rukholm:

Your proposal to conduct the above named research study at the Sudbury General Hospital has been reviewed and approved by the Bioethics Research Subcommittee.

Members of the Bioethics Research Subcommittee suggested that the physician-most-responsible be notified that his/her patient is involved in this research study.

Best wishes as you begin this study.

Sincerely,

R. M. Shine, M.D.
Chairperson
Bioethics Research Subcommittee

/pz

p.c. Sonia Peczeniuk
Assistant Executive Director - Nursing

LAURENTIAN UNIVERSITY
SCHOOL OF NURSING
Patient Consent Form

PROJECT TITLE: Family, patient and nurse experiences of supportive care in chronic cardiovascular illness

This is to certify that I, _____ (print name) hereby consent to participate in the research study conducted by Professor Ellen Rukholm. I understand that the purpose of this research study is to increase nurses' understanding of patients', family members' and their nurses' experiences of supportive nursing care during patients' hospitalisation for congestive heart failure as well as after hospital discharge. I understand that I will be interviewed at least twice. First, individually for approximately 30 minutes while I am hospitalised. Secondly, with my family after my discharge from hospital. The second interview will take place in my home at my convenience and will last a maximum of one hour. During both of these interviews questions will be asked regarding my experience of this illness.

There will be no direct benefits to the participants of this study, but there may be changes in patient care following completion of this study. The information gained in this study may help nurses working with other patients with chronic heart failure and their families.

I understand that there will be no health risks to me resulting from my participation in the research.

I understand that interviews will be tape-recorded. This recording will be used for research purposes only and that at the completion of the research, the tapes will be erased.

I understand that if I do not take part in this study, my refusal will in no way jeopardise my health care. I understand that I am free to refuse to answer specific questions without any personal ramifications. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

I understand that upon completion of this study, the findings will likely be published. I understand that I will not be identified by name in any discussions or publications of this research. A copy of the findings will be available in the School of Nursing (673-6589) and will be mailed to participants at their request. Should I have questions or concerns the researcher (Professor Rukholm) can be reached at 673 6589 or 522 4074.

Participant

Researcher

Date

LAURENTIAN UNIVERSITY
SCHOOL OF NURSING
Nurse Consent Form

PROJECT TITLE: Family, patient and nurse experiences of supportive care in chronic cardiovascular illness

This is to certify that I, _____ (print name) hereby consent to participate in the research study conducted by Professor Ellen Rukholm. I understand that the purpose of this research study is to increase nurses' understanding of patients', family members', and their nurses' experiences of supportive nursing care during patients' hospitalisation for congestive heart failure as well as after hospital discharge. I understand that I will be interviewed once for approximately thirty minutes at a time and location convenient for me.

There will be no direct benefits to the participants of this study, but there may be changes in patient care following completion of this study. The information gained in this study may help nurses working with other patients with chronic heart failure and their families.

I understand that there will be no risks to me resulting from my participation in the research. I understand that if I do not take part in this study, my refusal will in no way jeopardise my employment. I understand that I am free to refuse to answer specific questions without any personal ramifications. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I understand that interviews will be tape-recorded. This recording will be used for research purposes only and that at the completion of the research, the tapes will be erased. I understand that the information may be published, but my name will not be associated with the research.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

I understand that upon completion of this study, the findings will likely be published. I understand that I will not be identified by name in any discussions or publications of this research. A copy of the findings will be available in the School of Nursing (673-6589) and will be mailed to participants at their request. Should I have questions or concerns the researcher (Professor Rukholm) can be reached at 673 6589 or 522 4074.

Participant

Researcher

Date

LAURENTIAN UNIVERSITY
SCHOOL OF NURSING
Family Member Consent Form

PROJECT TITLE: Family, patient and nurse experiences of supportive care in chronic cardiovascular illness

This is to certify that I, _____ (print name) hereby consent to participate in the research study conducted by Professor Ellen Rukholm. I understand that the purpose of this research study is to increase nurses' understanding of patients', family members', and their nurses' experiences of supportive nursing care during patients' hospitalisation for congestive heart failure as well as after hospital discharge. I will be interviewed at least twice. First individually for approximately 30 minutes while my ill family member is hospitalised. Secondly, with my family after my family member has been discharged from hospital. The second interview will take place in my home, at my convenience and will last a maximum of one hour. During both of these interviews questions will be asked regarding my experience of this illness.

There will be no direct benefits to the participants of this study, but there may be changes in patient care following completion of this study. The information gained in this study may help nurses working with other patients with chronic heart failure and their families.

I understand that there will be no health risks to my ill family member (the patient) resulting from my participation in the research.

I understand that interviews will be tape-recorded. This recording will be used for research purposes only and that at the completion of the research, the tapes will be erased.

I understand that if I do not take part in this study, my refusal will in no way jeopardise my family member's (the patient) health care. I understand that I am free to refuse to answer specific questions without any personal ramifications. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

I understand that upon completion of this study, the findings will likely be published. I understand that I will not be identified by name in any discussions or publications of this research. A copy of the findings will be available in the School of Nursing (673-6589) and will be mailed to participants at their request. Should I have questions or concerns I know that the researcher (Professor Rukholm) can be reached at 673 6589 or 522 4074.

Participant

Researcher

Date

LAURENTIAN UNIVERSITY
SCHOOL OF NURSING
Patient Consent Form

PROJECT TITLE: Family, patient and nurse experiences of supportive care in chronic cardiovascular illness

This is to certify that I, _____ (print name) hereby consent to participate in the research study conducted by Professor Ellen Rukholm. I understand that the purpose of this research study is to increase nurses' understanding of patients', family members', and their nurses' experiences of supportive nursing care while I am enrolled in a cardiac rehabilitation programme. I understand that I will be interviewed at least twice. First, I will be interviewed individually for approximately 30 minutes, at a time and location of my choice. Secondly, I will be interviewed with my family. The second interview will take place in my home at my convenience and will last a maximum of one hour. During both of these interviews questions will be asked regarding my experience of this illness.

There will be no direct benefits to the participants of this study, but there may be changes in patient care following completion of this study. The information gained in this study may help nurses working with other patients with chronic heart failure and their families.

I understand that there will be no health risks to me resulting from my participation in the research.

I understand that interviews will be tape-recorded. This recording will be used for research purposes only and that at the completion of the research, the tapes will be erased.

I understand that if I do not take part in this study, my refusal will in no way jeopardise my health care. I understand that I am free to refuse to answer specific questions without any personal ramifications. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

I understand that upon completion of this study, the findings will likely be published. I understand that I will not be identified by name in any discussions or publications of this research. A copy of the findings will be available in the School of Nursing (673-6589) and will be mailed to participants at their request. Should I have questions or concerns the researcher (Professor Rukholm) can be reached at 673 6589 or 522 4074.

Participant

Researcher

Date

LAURENTIAN UNIVERSITY
SCHOOL OF NURSING
Nurse Consent Form

PROJECT TITLE: Family, patient and nurse experiences of supportive care in chronic cardiovascular illness

This is to certify that I, _____ (print name) hereby consent to participate in the research study conducted by Professor Ellen Rukholm. I understand that the purpose of this research study is to increase nurses' understanding of patients', family members', and their nurses' experiences of supportive nursing care for patients with congestive heart failure enrolled in a cardiac rehabilitation programme. I understand that I will be interviewed once for approximately thirty minutes at a time and location convenient for me.

There will be no direct benefits to the participants of this study, but there may be changes in patient care following completion of this study. The information gained in this study may help nurses working with other patients with chronic heart failure and their families.

I understand that there will be no risks to me resulting from my participation in the research. I understand that if I do not take part in this study, my refusal will in no way jeopardise my employment. I understand that I am free to refuse to answer specific questions without any personal ramifications. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I understand that interviews will be tape-recorded. This recording will be used for research purposes only and that at the completion of the research, the tapes will be erased. I understand that the information may be published, but my name will not be associated with the research.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

I understand that upon completion of this study, the findings will likely be published. I understand that I will not be identified by name in any discussions or publications of this research. A copy of the findings will be available in the School of Nursing (673-6589) and will be mailed to participants at their request. Should I have questions or concerns the researcher (Professor Rukholm) can be reached at 673 6589 or 522 4074.

Participant

Researcher

Date

LAURENTIAN UNIVERSITY
SCHOOL OF NURSING
Family Member Consent Form

PROJECT TITLE: Family, patient and nurse experiences of supportive care in chronic cardiovascular illness

This is to certify that I, _____ (print name) hereby consent to participate in the research study conducted by Professor Ellen Rukholm. I understand that the purpose of this research study is to increase nurses' understanding of patients', family members', and their nurses' experiences of supportive nursing care for patients with congestive heart failure enrolled in a cardiac rehabilitation programme. I will be interviewed at least twice. First, I will be interviewed individually for approximately 30 minutes. Secondly, I will be interviewed with my family while my ill family member is enrolled in a cardiac rehabilitation programme. The second interview will take place in my home, at my convenience and will last a maximum of one hour. During both of these interviews questions will be asked regarding my experience of this illness.

There will be no direct benefits to the participants of this study, but there may be changes in patient care following completion of this study. The information gained in this study may help nurses working with other patients with chronic heart failure and their families.

I understand that there will be no health risks to my ill family member (the patient) resulting from my participation in the research.

I understand that interviews will be tape-recorded. This recording will be used for research purposes only and that at the completion of the research, the tapes will be erased.

I understand that if I do not take part in this study, my refusal will in no way jeopardise my family member's (the patient) health care. I understand that I am free to refuse to answer specific questions without any personal ramifications. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

I understand that upon completion of this study, the findings will likely be published. I understand that I will not be identified by name in any discussions or publications of this research. A copy of the findings will be available in the School of Nursing (673-6589) and will be mailed to participants at their request. Should I have questions or concerns I know that the researcher (Professor Rukholm) can be reached at 673 6589 or 522 4074.

Participant

Researcher

STANDARD EXPLANATION OF THE STUDY

I am very interested in documenting and understanding the work that nurses do in caring for chronic heart failure patients and their families. I am particularly interested in finding out what patients and their families think supportive nursing care means. I am also interested in finding out what nurses think supportive nursing care means to patients and their families in a chronic heart failure situation. Too often, the work written about nursing is not from the views of the patients, their families, and the nurses who are providing bedside nursing care. I am studying and recording patients', family members', and nurses' views about supportive nursing care.